

Understanding Lived Experiences and Contextual
Realities of Ebola Outbreaks: A Case Studies
Approach in Western Uganda

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This dissertation is submitted to the University of Dublin in
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Declaration

25th February 2018

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Caroline Sarah Ryan
25th February 2018

Executive Summary

Ebola Virus Disease (EVD) is caused by a highly infectious and fatal *filovirus* of zoonotic origin among human and primate populations on the African continent. First recorded in 1976, EVD is classified as a potential ‘public health emergency of international concern’ (PHEIC) under the revised International Health Regulations (2005). The unprecedented Ebola outbreak that emerged in West Africa in 2013 conveys how infectious diseases remain very much part of global challenges in the twenty first century. Actors and institutions governing global health perceive EVD in terms of an imminent threat to global health security. This influences response interventions, which predominantly focus on surveillance, emergency response mechanisms and containment. EVD outbreaks have always emerged from impoverished areas within Africa where the greatest proportion of the global burden of disease already exists. Few studies have explored local perspectives towards these outbreaks relative to the contextual realities from which they emerge. No study has considered the approach, consequences, or aftermath of international interventions on the affected individuals, communities, and their health systems.

The extant literature conveyed that the majority of knowledge reported around EVD outbreaks to date is skewed towards a biomedical understanding from the positive perspective. A justification for the study was to address a gap in the literature to explore the concept of ‘southern theory’ through the inclusion of local interpretations and lived experiences around EVD outbreaks. The study used an inductive research approach following an interpretive epistemology and case study design. Using two case studies, the study explored the contextual realities and lived experiences of two communities in western Uganda, Bundibugyo, and Kibaale, who experienced EVD outbreaks in 2007 and 2012 respectively. Multiple qualitative methods were employed including 25 in depth interviews, non-participant observations and document analysis. Analysis of the data adopted a grounded theory approach using Strauss and Corbin’s

cyclic three step technique. Five main themes emerged with ‘disempowerment during EVD outbreaks’ as the overarching theme of the study. Horbst and Wolfe’s (2014) concept of *medicoscapes* was explored as a framework to make sense of the dynamics and linkages between the themes and categories and how these related to global processes that determined health outcomes.

The first main theme of the study was ‘a behaviour blame narrative’. Cultural theory was applied as an anthropological perspective to understanding the concept of blame. Blame was explored from three perspectives, blame of the individual, blaming an adversary and finally blame of larger structural forces was considered. The second main theme to emerge from the analysis was the structural determinants of delayed diagnosis and nosocomial transmission. This theme emerged from the categories of institutional hierarchies and weak health systems as underlying factors that facilitated a rational explanation to events that led to amplification of the virus and several deaths within the community and of health workers before external intervention.

‘Social realities’ of Bundibugyo and Kibaale was the third main theme that emerged from the study and demonstrated how the social determinants of poverty and war were subordinated to a cultural epidemiology. Poverty and its associated challenges of poor living conditions, alternative means of sourcing food such as forest activities and inaccessibility to conventional health services emerged as making the poor vulnerable to infectious diseases including EVD in both contexts. These social determinants are linked to larger structural forces of a global capitalist system that maintains the inequalities in global development underlying poverty in Sub Saharan Africa. A scramble for resources in neighbouring DRC feeding into this globalised economy has resulted in the death and displacement of millions of Congolese and underlies the refugee burden in Western Uganda including Bundibugyo and Kibaale. The fourth theme from the study was EVD exceptionalisation and explored how a global narrative exoticised EVD and influenced understandings and response interventions to outbreaks. Several consequences resulted from EVD

exceptionalisation that included misdiagnosis, fear, neglect, stigma, and undermining endemic disease. EVD exceptionalisation influenced a global health security agenda and guided response interventions. An outcome of this identified in both case studies was a loss to the security of the individual. The final theme that emerged from the study was empowerment where the contribution of local capacity and mechanisms of coping were employed during the interim period of both outbreaks before external intervention.

Overall, the findings from this study demonstrate the contextual realities from where EVD outbreaks emerged in western Uganda and the lived experiences of those affected. The main themes that emerged from the analysis were common across both case studies. The findings demonstrate that current response interventions fail to support health system strengthening and focus on 'global' security not necessarily on the security and welfare of the individual in African contexts. This study contributes to an existing knowledge imbalance by providing a broader and deeper understanding of how globalisation processes impact on health outcomes and disempowerment of the individual. This has important policy implications in terms of the people-centered mission underscored by the UN Commission on Human Security. It also has important theoretical implications by conveying the importance of applying explorative methods as a means of analysing the deeper dynamics hidden under dominant narratives.

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List of Acronyms and Abbreviations

A

ADF: Allied Democratic Front
AFNET: African Field Epidemiology Network
AHO: African Health Workforce Observatory
ARV: Anti-Retroviral Therapies

B

BDBV: Bundibugyo virus

C

CDC: Centre for Disease Control and Prevention
CHOGM: Common Heads of State General Meeting
CIRMF: Le Centre international de recherche médicales de
Franceville
CFR: Case Fatality Rate

D

DIC: Disseminated Intravascular Coagulopathy
DRC: Democratic Republic of the Congo
DTF: District Task Force

E

EBOV: Ebola virus
EHV: Ebola Haemorrhagic Virus
ENT: Ears, Nose & Throat
ETU's: Ebola Treatment Units
EVD: Ebola Virus Disease
EWARN: Early Warning & Response Network (South

Sudan)

ES: Escapable Stress

F

FAO: United Nations Food and Agricultural Organisation

G

GOARN: Global Outbreak & Alert Response Network

H

HC: Health Centre
HDI: Human Development Index
HIV: Human Immunodeficiency Virus
H1N1: Influenza A virus subtype H1N1
H5N1: Highly Pathogenic Asian Avian Influenza
HPAI: Highly Pathogenic Avian Influenza

I

IBEAC: Imperial British East African Company

IDI: Infectious Disease Institute
IDI: In-depth interview (when used to cite excerpts)
IFRD: International Federation of the Red Cross
IgG: Immunoglobulin G
IHR: International Health Regulations
IMF: International Monetary Fund
IMTF: Inter-Ministerial Task Force
IS: Inescapable Stress

L

LIC: Low Income Countries
LMIC: Low and Middle Income Countries

M

MARV: Marburg virus
MDR-TB: Multiple Drug Resistant Tuberculosis
MoH: Ministry of Health (Uganda)
MONUSCO: United Nations Stabilization Mission in the Democratic Republic of the Congo
MSF: Médecins Sans Frontières

N

NEPAD: New Partnership for African Development
NGO: Non-Governmental Organisation
NTF: National Task Force

O

OHCEA: One Health Central and East Africa

P

PCR: Polymerase Chain Reaction
PHEIC: Public Health Emergency of International Concern
PLHIV: Persons Living with HIV
PRRS: Porcine Reproductive & Respiratory Syndrome

R

RESTV: Reston virus
RNA: Ribonucleic acid
RT-PCR: Reverse Transcriptase PCR

S

SARS: Severe Acute Respiratory Syndrome
SIT: Social Identity Theory
SUDV: Sudan virus
SiRNA: Small Interfering Ribonucleic Acid

T

TAFV: Tai Forest ebolavirus

U

UBOS: Uganda Bureau of Statistics
UK: United Kingdom

UNC: Uganda National Congress
UNDP: United Nations Development Programme
UNHCR: United Nations High Commission for Refugees
UNICEF: United Nations International Children's
Emergency Fund
UNMEER: United Nations Ebola Emergency Response
UPC: Uganda People's Congress
UPDF: Ugandan Patriotic Democratic Front
URCS: Ugandan Red Cross Society
USA: United States of America
USAID: United States Agency of International

Development

UVRI: Uganda Virus Research Institute

V

VHF: Viral Haemorrhagic fever

VHT: Village Health Team

W

WFP: World Food Programme

WHA: World Health Assembly

WHO: World Health Organisation

Chapter 1: Introduction

1.1 Purpose of the Study

Emergence of epidemics of international concern such as Ebola Virus Disease (EVD), are largely understood from a biosecurity perspective. This may represent an imbalance in knowledge that subordinates the social, political, and cultural determinants for their emergence at local level. Current narratives and response interventions towards EVD outbreaks may also denote an imbalance in the power dynamics between the global North and South within the realm of global health.

“Narratives interplay in ways shaped by politics and power. Not all lead to response pathways. Some may remain marginalized or even hidden” (Leach & Dry, 2010, p.15).

In an attempt to address this imbalance, the main aim of this study was to draw out the ‘southern voice’ in the aftermath of two EVD outbreaks that occurred in Bundibugyo and Kibaale districts in Western Uganda in 2007 and 2012 respectively. It was felt that a deeper understanding of the contextual realities and lived experiences of the communities who directly experienced these EVD outbreaks may provide for a more balanced contribution of knowledge towards informing future policy responses within the realm of global health security.

The study also examines the state of the ‘post Ebola’ health systems as a result of previous international interventions in Bundibugyo and Kibaale with the purpose of providing primary evidence of the level of sustainable health system strengthening if any result from international interventions during EVD outbreaks.

No previous studies have analysed the dynamics linking the contextual realities and lived experiences of Ebola outbreaks with the dynamics of global health interventions. There are few studies that gave voice to those directly affected by EVD outbreaks in the past (Hewlett & Amola, 2003; Hewlett & Hewlett, 2008; Matua, 2014). Missing from the literature is a narrative or ‘southern theory’ emerging from within the self-knowledge and understanding of the society from which these outbreaks occur. By employing an anthropological perspective the study attempts to reduce this gap between those who narrate and guide responses to Ebola outbreaks from those who experience the realities on the ground. Anthropology has more recently been recognized as an important framework for analysis in global health (Dry & Leach, 2010; Larkan *et al.*, 2015). According to Horbst and Wolf, (2014, p.183) an anthropological means of analysis can be used to capture, both theoretically and analytically “the highly complex, heterogeneous layers, process and results of globalization in the field of health, care and international support.” Larkan *et al.* (2015) supports the role of employing an anthropological perspective in reviewing and critiquing epidemics in terms of their geopolitics, cultural and social understanding. Unlike earlier studies on EVD outbreaks, the focus of this study explores the lived experiences and contextual realities of the persons and sites where two EVD outbreaks occurred and responded to as global public health crises. It also attempts to compare local and global perceptions and narratives around EVD emergence and response interventions aiming to identify gaps in current knowledge of understandings. This research is timely following the largest ever EVD outbreak in history as experienced by the people of West Africa. Whilst the proposal for this study began prior to the West African outbreak, which captured international public and policy attention, the research could not be undertaken in isolation of this event as it ran parallel to the study and served as a reminder that social research occurs within a real world context. Since the West African EVD outbreak ended an EVD outbreak has since been recorded in the DRC in May 2017 (WHO, 2017).

1.2 Background

1.2.1 Uganda

Uganda is a landlocked country in East Africa straddling the equator. Uganda shares borders with South Sudan to the north, Kenya to the east, Lake Victoria, Tanzania and Rwanda to the south, and the Democratic Republic of the Congo (DRC) to the west.

Centuries of migratory movements, environmental management and agro-pastoral systems between the first millennium B.C and the sixteenth century created diverse groups of settlers across this Great Lakes Region, within which lies Uganda (Chrétien, 2006). Bantu and Nilotic speaking groups divide Uganda linguistically from north to south. From clans emerged kingdoms and under colonialism, Uganda became a British Protectorate administered through the Buganda Kingdom of Central Uganda between 1894 and 1961. Apollo Milton Obote became the first Ugandan President following independence in 1961. Idi Amin overthrew Obote in a coup ten years later in 1971. Obote was returned to power in 1981 by an election process that was rejected by Yoweri Museveni's National Resistance Army (NRA) that led to the Ugandan bush war between 1981 and 1986. From 1986 under Yoweri Museveni the country transitioned under a multiparty political system and President Museveni was re-elected in 2005, 2011 and 2016. Since 1986 Uganda has remained politically stable and the constitution of Uganda protects most civil, political, economic and social rights.

Eighty per cent of Uganda's economy derives from the export of primary agricultural products with tea as the most important followed by coffee, fish, cocoa, copper, cotton and oil (World Bank, 2015). Ranked at 164 out of 187 countries in human development, Uganda remains one of the world's poorest countries. The average gross domestic product per capita purchasing power parity (PPP) in United States Dollars (USD) is \$1,851 with over 84% of the population living below the poverty line (World Bank, 2015). The current population of Uganda is estimated at 34.6 million with a fertility rate of 5.8 births per woman (UBOS, 2014). Subsistence agriculture is undertaken by 69% of a predominantly rural based population. Fifty one per cent of the population is female and 56.7% are under 18 years of age resulting in a high household dependency ratio making an exit from poverty challenging (UBOS, 2014). This large population of youth creates a high demand on education and health services but is also viewed as a measure of potential economic development as an emerging labour pool.

Uganda remains burdened by communicable diseases many of which have long been eradicated from high and middle-income countries (UNDP, 2015). The number of people living with HIV (PLHIV) has also increased in the last decade. This is partly due to greater longevity among infected persons due to increased access to anti-retroviral therapies (ARV) but is also due to an increase in new infections diagnosed (HIV and AIDs Uganda Country Profile Report 2014). Outbreaks of Ebola, Marburg, Hepatitis E, cholera and plague have all occurred in recent years and outbreaks of polio emerged in 2009, 2010 and

2011 (Athumani, 2015). Maternal and perinatal problems continue to contribute towards high mortality rates in Uganda (UBOS, 2012). In addition there is a growing increase in non-communicable diseases including cancer and diabetes particularly among a growing middle class (Schwartz, 2014). There are wide disparities in health across the country with rural communities carrying the main burden of infectious diseases (Mathers & Ezzati, 2007). Table 1.1 conveys improvements in some development indicators between 2002 and 2015 but progress remains slow.

TABLE 1.1: DEVELOPMENT INDICATORS 2002 -2015

Indicator	2002	2012 -2015
Life expectancy at birth	43 years	59.2 years (2015)
HIV/AIDS prevalence rate	6.1%	7.3%
Safe water access	52%	75% (2012)
Under five mortality rate	152 per 1,000	54 per 1,000

Source: *AHWO, 2009, World Bank, 2015*

1.2.2 Structure of Uganda’s Health System

The Ugandan health system structure is based on a decentralized framework where the district is responsible for all health care facilities within the district except the regional referral hospitals, where they exist (Kamwesiga, 2011). Table 1.2 outlines the services provided at each level of service delivery according to the Health Sector Strategic Plan 2005/2006 to 2010/2011.

Table 1.2: Levels of Health Service Delivery outlined in the Health Sector Strategic Plan 2005/2006 to 2010/2011

Infrastructure Level	Administrative Level	Target Number	Services Provided
HCI	Village	1,000	Community based preventive and promotive health services. Village health committee or similar status.
HCII	Parish	5,000	Preventive, promotive and out patient, curative health services.

			Community outreach.
HCIII	Sub-county	20,000	Preventive, promotive, outpatient, curative, maternity, inpatient services and laboratory services.
HCIV	County	100,000	Preventive, promotive, outpatient, curative, maternity, inpatient services, emergency surgery, blood transfusion, and laboratory services.
District	General Hospital	500,000	In addition to the services provided at HCIV other general services are provided. These include in-service training, consultation and research to community based health care programmes.
Regional	Regional Referral Hospital	2,000,000	In addition to the services offered at the general hospital level special services are offered at this level. Such services include psychiatry, ear, nose and throat (ENT), ophthalmology, dentistry, intensive care, radiology, pathology, higher-level surgical and medical services.
National Referral	National Referral Hospital	24,000,000	These provide comprehensive specialist services. In addition they are involved in teaching and research.

Source: AHWO (2009) Human Resources for Health Country Profile – Uganda, Africa Health Workforce Observatory, p.20

In reality, however, the components within the structure as described here do not always equate to the reality on the ground. While the system maintains a bottom up approach from primary to tertiary level, access to healthcare in this system remains weak due to inadequate health financing and resources. Village Health Teams (VHT) are not always available and the Health Centre (HC) levels are often understaffed and under resourced. Despite the abolition of user fees, access to health care services and medications in public

institutions frequently depend on informal fees (McPake *et al.*, 1999; Xu *et al.*, 2006; Kiwanuka *et al.*, 2008; Orem *et al.*, 2011). In a national service delivery survey over 30% of women accessing antenatal care in public facilities were reported to have paid informal user fees (UBOS, 2004).

An increasing number of refugees from neighbouring country conflicts particularly from South Sudan, eastern DRC, Somalia and Burundi add to growing demands on Uganda's resource poor public health system (Komakesh *et al.*, 2014; Kreibaum, 2014; MCPake *et al.*, 2015).

1.2.3 Ebola Virus Disease

Ebola Virus Disease (EVD) is caused by a highly infectious *filovirus* known to cause high mortality rates among human and primate populations on the African continent (Rouquet *et al.* 2005; Feldmann *et al.*, 2011; Beeching *et al.*, 2014; Bray *et al.*, 2015). Epizootic outbreaks and secondary transmissions have also occurred beyond Africa (WHO, 2009; Miranda & Miranda, 2011; Uyeki *et al.* 2016). Five species of Ebola virus have been isolated to date, *Zaire ebolavirus*, *Sudan ebolavirus*, *Bundibugyo ebolavirus*, *Tai Forest ebolavirus*, formerly *Ebola d'Ivoire Coast* and *Reston ebolavirus*. The virus is zoonotic and tree roosting bats including those from the *Pteropodidae* family (*fruit bats*) are suspected as the natural hosts of the virus (Towner *et al.* 2007; Towner *et al.* 2009; Leroy *et al.*, 2009; WHO, 2012a; Wood *et al.*, 2012). However a definitive reservoir host remains unidentified. The virus is thought to infect humans through handling or eating meat products or materials carrying the virus from an infected wild animal, however natural host transmission to humans cannot be ruled out (Shoemaker *et al.*, 2012). Human-human transmission mainly results from contact with body fluids of an infected patient, most commonly occurring during patient care or burial practices, making those involved in primary health care within households and health care facilities particularly vulnerable during epidemics. Initial symptoms of infection are non-specific making a tentative diagnosis from other common endemic fevers in African contexts such as malaria, typhoid or diphtheria challenging.

The first recorded EVD outbreaks in Africa occurred almost simultaneously in former Zaire and Sudan in 1976. Since then there have been over 25 outbreaks across 20 countries in and beyond the African continent (Table 1.3). Among these was the unprecedented outbreak that occurred in West Africa between 2013 and 2016 with 28,616-recorded cases

and 11,310 fatalities on 10th June 2016 (WHO, 2016b).

Table 1. 3: History of Ebola Outbreaks 1976 to 2017

Year	Country/Region	Virus Subtype	Cases	Deaths	Case Fatality Rate
2017	DRC	<i>Ebola Zaire</i>	32	4	13%*
2014	DRC	<i>Ebola Zaire</i>	66	49	74%
2014 -2016	Sierra Leone	<i>Ebola Zaire</i>	14122	3956	28%
2014 -2016	Liberia	<i>Ebola Zaire</i>	10675	4809	45%
2014 -2016	Guinea	<i>Ebola Zaire</i>	3804	2536	67%
2014	Nigeria	<i>Ebola Zaire</i>	20	8	40%
2014	Senegal	<i>Ebola Zaire</i>	1	0	0%
2015	Spain	<i>Ebola Zaire</i>	1	0	0%
2014	USA	<i>Ebola Zaire</i>	4	1	25%
2014	Mali	<i>Ebola Zaire</i>	8	6	75%
2015	UK	<i>Ebola Zaire</i>	1	0	0%
2015	Italy	<i>Ebola Zaire</i>	1	0	0%
2012	Uganda	<i>Ebola Sudan</i>	7	4	57%
2012	DRC	<i>Ebola Bundibugyo</i>	77	36	47%
2012	Uganda	<i>Ebola Sudan</i>	24	17	71%
2011	Uganda	<i>Ebola Sudan</i>	1	1	100%
2008-2009	DRC	<i>Ebola Zaire</i>	32	15	47%
2008	Philippines	<i>Ebola Reston</i>	6	0	0%
2007	Uganda	<i>Ebola Bundibugyo</i>	149	37	37%
2007	Democratic Republic of Congo (DRC)	<i>Ebola Zaire</i>	264	187	71%
2005	Republic of Congo	<i>Ebola Zaire</i>	12	10	83%
2004	Sudan	<i>Ebola Sudan</i>	17	7	41%
2004	Russia	<i>Ebola Zaire</i>	1	1	100%
2003-2004	Republic of Congo	<i>Ebola Zaire</i>	35	29	83%
2002-2003	Republic of Congo	<i>Ebola Zaire</i>	143	128	90%
2002	Gabon, Republic of Congo	<i>Ebola Zaire</i>	11	10	90%
2001-2002	Gabon	<i>Ebola Zaire</i>	59	44	75%
2000-2001	Uganda	<i>Ebola Sudan</i>	425	224	53%
1996	South Africa (ex	<i>Ebola Zaire</i>	1	1	100%

	Gabon)				
1996	Gabon	<i>Ebola Zaire</i>	60	45	75%
1996	Russia	<i>Ebola Zaire</i>	1	1	100%
1996	USA, Philippines	<i>Ebola Reston</i>	Epizootic	0	0%
1996	Gabon	<i>Ebola Zaire</i>	37	21	58%
1995	Zaire	<i>Ebola Zaire</i>	315	254	81%
1994 -1995	Gabon	<i>Ebola Zaire</i>	52	31	60%
1994	Cote d'Ivoire	<i>Ebola Tai Forest</i>	1	0	0%
1992 - 1993	Italy, Philippines	<i>Ebola Reston</i>	Epizootic	0	0%
1989-1990	USA	<i>Ebola Reston</i>	Epizootic, 4-6	0	0%
1979	Sudan	<i>Ebola Sudan</i>	34	22	65%
1977	Zaire	<i>Ebola Zaire</i>	1	1	100%
1976	United Kingdom	<i>Ebola Sudan</i>	1	0	0%
1976	Sudan	<i>Ebola Sudan</i>	284	151	53%
1976	Zaire	<i>Ebola Zaire</i>	318	280	88%

Sources: WHO (2012), updated 19th May 2017; CDC (2016); Georges et al., 1999)

Uganda has experienced five of these Ebola outbreaks of various sizes and scale between 2000 and 2012 (Figure 1.1).

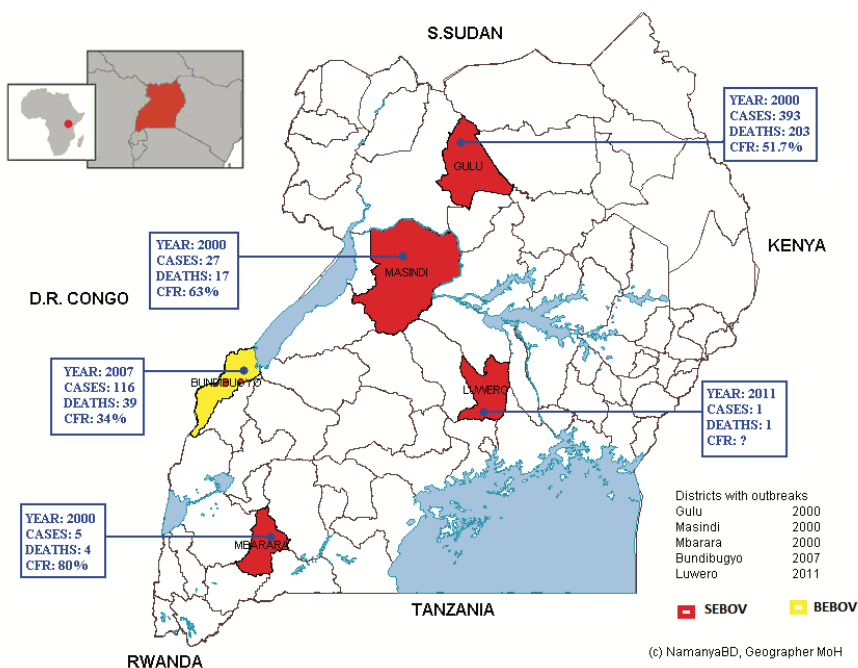


Fig. 1.1 Map of previous Ebola outbreaks in Uganda between 2000 and 2011(exclusive of Kibaale 2012).

Source: Namanya D.B, Geographer, Makerere University, Uganda (Note: Bundibugyo cases not aligned with WHO figures of 149 cases and 37 deaths (WHO, 2012a).

1.2.4 Overview of Ebola Outbreaks in Uganda 2000 -2012

The first and largest outbreak of EVD occurred in Northern Uganda in August 2000 in Rwot-Obillo, a village 14 kilometres north of Gulu town. This outbreak later spread to Masindi and Mbarara districts in West and Southwestern Uganda (Okware, 2012). An official announcement of the outbreak was given on the 20th October 2000 following the death of three student nurses at St. Mary's Hospital, Lacor (Okware, 2012). Dr. Matthew Lukwiya directed the management of the outbreak at Lacor Mission Hospital prior to external intervention and later died following infection with the virus in December 2000. Médecins Sans Frontières (MSF) and the Ministry for Health (MoH) managed cases admitted to the Regional Referral Hospital. A District Task Force (DTF), National Task Force (NTF) and Inter-Ministerial Taskforce (IMTF) coordinated the response at district and national level. The international response to the outbreak was coordinated under the Global Outbreak and Alert Response Network (GOARN) an umbrella network under the World Health Organisation (WHO). In total 224 deaths were reported from 425 cases including 19 health care workers (Okware *et al.*, 2002).

On the 29th November 2007 the Ugandan Ministry for Health officially announced an outbreak of EVD in Bundibugyo district, Western Uganda. According to MacNeil *et al.* (2010) anecdotal reports suggested an illness consistent with EVD arose in the area around August. Following the November announcement a NTF was generated comprising the Ugandan MoH, WHO and international partner organisations including MSF, Switzerland, African Field Epidemiology Network (AFNET), International Federation of the Red Cross (IFRD), Centre for Disease Control and Prevention (CDC), the United Nations International Children's Emergency Fund (UNICEF) and the World Food Programme (WFP). Cases were managed at Kikyoo Health Centre IV in Bughendera County and at Bundibugyo General Hospital in Bundibugyo town. In total 149 cases were reported and 37 people died including four health care workers (WHO, 2012a). The outbreak was declared officially over on the 20th February 2008.

In May 2011 a single case fatality by Sudan virus killed an eleven-year old girl in Luweero district, Central Uganda (Figure 1.2). The girl was admitted to Bombo Medical Hospital from Nakisamata village fifty kilometres north of Kampala with non-responding fever and vaginal hemorrhaging, and died within hours of admission. Samples confirmed EVD and two days later teams from the MoH, CDC and MSF arrived to support surveillance and collect samples from four in-contact family members. This was a single isolated incident

and the source was suspected as a zoonotic contact but this remains unconfirmed (Shoemaker *et al.*, 2012).

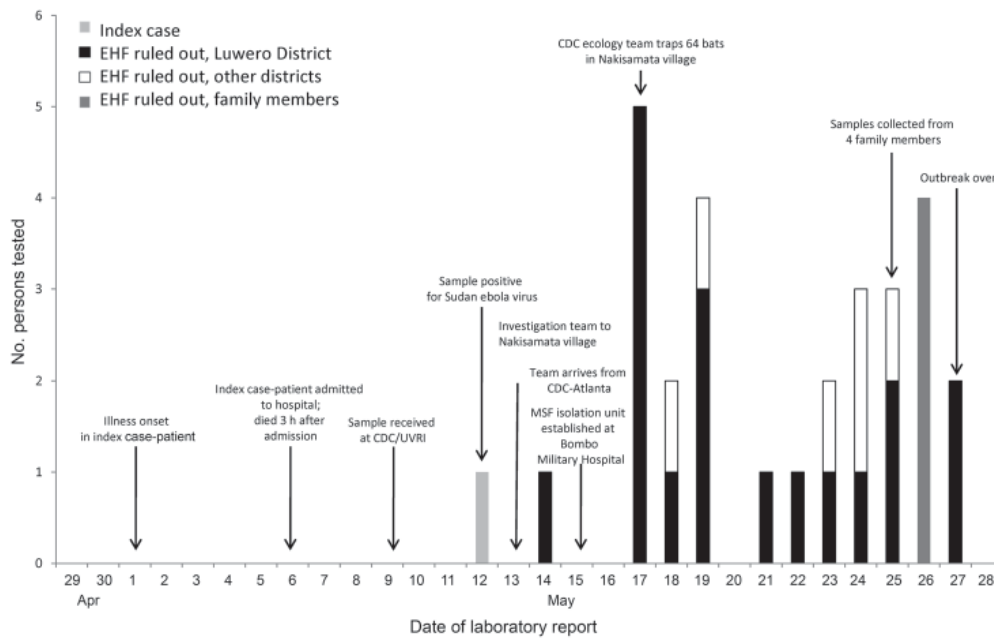


Fig. 1.2 Timeline of Sudan Ebola Virus 2011

(Source: Shoemaker, *et al.*, 2012)

Uganda again notified WHO of an Ebola outbreak in Kibaale district, Western Uganda on 6th July 2012. The Uganda Virus Research Institute (UVRI) at Entebbe isolated *Sudan virus*. Samples were also sent to CDC, Atlanta in the United States of America (USA) for additional analysis and sequencing. The outbreak was officially confirmed over on the 24th August. A total of 13 probable, 11 confirmed cases and 17 deaths were reported during this outbreak (WHO, 2012b). Twelve of these deaths occurred within one family.

Within the same year, in October 2012 a second Ebola outbreak emerged in Central Uganda in Luweero and Kampala districts, spreading to Rukungiri, Mbarara and Ibanda districts (WHO, 2012). This outbreak resulted in seven confirmed cases and four deaths. Twelve suspected cases were admitted to an isolation facility at Bombo Military Hospital in Luweero district. A second isolation unit was set up at Mulago, National Referral Hospital in Uganda’s capital, Kampala. The last reported case was reported on the 18th December and active surveillance and public information continued until the brief outbreak was declared officially over on the 16th January 2013. Since 2012 no further outbreaks of EVD have been reported in Uganda.

International assistance has improved surveillance and diagnosis of EVD in Uganda as evidenced from earlier intervention during more recent outbreaks experienced in 2011 and 2012. An emphasis on surveillance and rapid response to identify and contain emerging infectious diseases including EVD has more recently been placed as a priority in health development.

1.2.5 Global Health Security

Global health security is defined as

“The activities required, both proactive and reactive, to minimize vulnerability to acute public health events, that endanger the collective health of populations living across geographical regions and international boundaries” (WHO, 2007a, p.1).

The term ‘global health security’ originated as a concept from fears of bioterrorism, influenced by allegations that some countries or terrorist organisations may be storing smallpox virus (WHO, 2007b). Since its certified eradication in 1979, smallpox has become a major threat to global health. In 2001 an anthrax threat through the USA postal system has evolved global health security to incorporate the concept of a ‘war on terror’ (Collier *et al.*, 2004).

Influenced by the 2003 Severe Acute Respiratory Syndrome (SARS) outbreak in China together with other novel virus outbreaks including EVD, Marburg, H1N1 swine influenza and H5N1 highly pathogenic avian influenza (HPAI), the International Health Regulations (IHR) were revised by the World Health Organisation in 2005 (Leach & Hewlett, 2010). The revised regulations were adopted by the 58th World Health Assembly (WHA) for implementation in June 2007, legally binding all 194 member states to timely report on major ‘events’ that potentially pose as “public health emergencies of international concern” (PHEIC), (WHO, 2008a). The main objective of the revised IHR is based on creating an integrated international surveillance network to contain threats to global health security when and where they occur.

Traditional distinctions between national and international public health have changed under processes of globalisation, and the landscape of global health including its actors and institutions have changed dramatically over the past three decades (Dry, 2010). The revised IHR have been criticized as an example of how the predominantly western

institutions governing global health have prioritized ‘global health security’ in health development by emphasising surveillance and response interventions towards novel disease outbreaks that are of most concern to them. While these novel virus outbreaks, classified as ‘emerging infectious diseases’, may be perceived as potential pandemic threats warranting ‘global’ health priority, the burden of such epidemics when they occur are mostly borne by impoverished communities in sub-Saharan Africa.

The revised IHR have also been criticized for providing no formal source of funding to low or middle-income countries (LMIC) to make the required investments deemed necessary to strengthen their health systems and fulfill these obligations (Fischer *et al.*, 2011). As a result, LIC’s in particular are almost totally dependent on external support from international donors in the form of humanitarian intervention when such outbreaks occur. Unfortunately this does not equate into robust health systems that can maintain a sustainable preparedness and response capacity to buffer the impacts of such events, particularly prior to confirmed diagnosis and announcement as witnessed in West Africa between 2013 and 2016.

1.2 Problem Statement

The dominant narrative surrounding EVD outbreaks focus on a highly virulent pathological agent that poses a major threat to ‘global’ health security. This narrative dominates media reports, the scientific literature and donor-funded programmes across sub-Saharan Africa (CDC, 1998; Institute of Medicine, 1994; Lashely, 2006; USAID, 2016). This northern oriented perspective advances a biological understanding of EVD that has become increasingly shaped by a war on terror and informs ‘best practice’ to contain it (Collier *et al.*, 2004).

Whilst pandemic preparedness is justified, and a focus on strengthening response capacity to containing highly infectious diseases at source through global collaborations can be viewed as good news for the impoverished communities most at risk, shifting control and reliance for such interventions onto a ‘global’ stage dominated by western actors and institutions may reflect a bias towards North serving interests.

Uganda has been described as a success story in the past in terms of surveillance and control of previous EVD outbreaks (Okware *et al.*, 2002). This conclusion was based on an evaluation of output indicators from an integrated Regional Surveillance Strategy one year

after implementation (Lamunu *et al.*, 2002). The sustainability of this initiative was however questionable as all EVD outbreaks in Uganda were based on fragile health infrastructure and almost totally dependent on external assistance (Calain, 2007). Apart from awareness campaigns on emerging pandemic threats aimed at health ministries and higher institutes of education in the region (USAID, 2016), awareness does not always equate into broader health system strengthening in terms of physical preparedness on the ground. Since previous outbreaks little has been implemented to develop the response capacity of impoverished health systems towards managing future outbreaks. It is these health systems, particularly the local ministries, hospitals and health centres that are central to the management and control of EVD outbreaks when and where they occur. The reality is that health facilities in rural areas remain over burdened with growing populations and endemic health issues and remain under resourced in terms of infrastructural, financial and human resources for health. Despite a global health agenda focusing on health security, Uganda remains vulnerable to future Ebola outbreaks.

1.3 Research Objectives and Guiding Questions

The main objective for this research followed a scoping of the extant literature but it did not emanate entirely from it. The researcher's experience in the field also influenced the focus of the study and will be outlined in more detail in chapter three. Feeling that a deeper understanding of the lived experiences and contextual realities of EVD outbreaks and their responses can make an important contribution to understanding Ebola outbreaks and future interventions, the researchers main objective for the study was:

To understand the contexts from where two Ebola outbreaks emerged in western Uganda in 2007 and 2012, and how these outbreaks and the external interventions towards them were locally understood, experienced and globally determined.

From historical accounts health facilities across east and central Africa became the epicenters of previous Ebola outbreaks. It was from within these health facilities that those infected, either contracted the disease, were treated for its symptoms and survived or in many cases for both patients and health care workers, it was the place where they died. The study considered these health facilities in terms of spaces from where health care workers and support staff experienced EVD outbreaks, where external organisations set up their bases, logistics and response interventions, from where community events, meetings and

media reports were delivered and which continue functioning today two and seven years in their aftermath.

In a quest to better understand local perceptions, lived experiences and the contextual realities of Ebola outbreaks and their interventions in western Uganda the following four specific research questions were developed.

1. What are the contextual realities of Bundibugyo and Kibaale from where two Ebola outbreaks emerged in 2007 and 2012 respectively?
2. How were EVD outbreaks understood from local, national and global perspectives in Bundibugyo and Kibaale in 2007 and 2012?
3. What were the lived experiences of Ebola outbreaks before, during and in the aftermath of international interventions in Bundibugyo and Kibaale?
4. What were the determinants and consequences of global health interventions before, during and in the aftermath of the Ebola outbreaks in Bundibugyo and Kibaale?

According to Eisenhardt (1989) having clear objectives going into the research is important as they guide the researcher who could otherwise become overwhelmed in a sea of data.

1.4 Significance of the Study

The focus of the first case study takes place within the district of Bundibugyo, Uganda's most western district where an EVD outbreak was experienced in 2007. The second case study is located in the mid-western district of Kibaale where an Ebola outbreak was experienced in 2012. Inclusion of lived experiences of EVD epidemics from within the context of the health facilities where they are managed and explored over a wider time-scale may contribute towards a broader understanding of their occurrence. In addition to a broader understanding of the contextual realities and lived experiences during and following emergence of EVD epidemics in western Uganda, factors may emerge that can

inform more effective and sustainable responses towards future prevention and management of such outbreaks. At policy level this is significant because how a disease or epidemic is understood informs its response. The findings of the study are therefore relevant to the Ugandan MoH, international, regional and national policy makers, multilateral and bilateral agencies, civil society, students and local health workers within communities in Uganda in terms of broadening current understanding of EVD emergence, management and response for planning policy and response interventions towards future epidemics.

1.5 Thesis Overview

Chapter two commences with an outline of the search strategy used to inform the literature review. The extant literature was analysed for its relevance and meaningfulness in terms of providing a basis for critical discussion for the emergent findings. The first section focuses on Uganda's political history from clans, kinships, colonialism, neocolonialism and international development. The second section defines and describes EVD in biological terms comprising the virus species, epidemiology and case fatality rates. It then goes on to describe an array of non-specific clinical symptoms, its pathogenesis, diagnosis, management, recent advancements and innovations and the WHO case definition used during epidemic investigations. Section three examines the literature from an interdisciplinary perspective and explores some of the anthropological, cultural and social determinants of disease and epidemics. The fourth section focuses on the evolution and geopolitics of global health and the institutions that govern global health issues and policy agendas. It takes an overview of the actors, networks and institutions comprising the contemporary realm of global health and the position of EVD within that landscape, specifically as a threat to global health security.

Chapter three presents the research methodology. It begins with an overview of the theoretical assumptions including the researchers theoretical and practical position in the study. Justification for using a qualitative study design and the role of the two case studies are outlined. This is followed with a description of the process of data collection including selection criteria for both case study sites and the study participants. A description of the protocols for access, ethics and participant consent and how they were operationalised within the study are described. This section concludes by rationalising the role and approach for each of the data collection methods engaged in the study. Section five

outlines the analysis of the study using a technique adopted from grounded theory. The *Medioscapes concept* is described and justification for its role as a framework to present the data findings is outlined. The final section focuses on informing the reader how the study methodology aimed at adhering to the standards of 'good research' in terms of reliability and validity of the findings.

Chapter four and five are findings chapters where research themes, categories, codes and excerpts from the analysis are presented as 'Data Presentations'.

Chapter six is the discussion chapter where the emergent themes are critiqued and developed from existing theories. From here the concepts of power and disempowerment within international development are discussed in relation to Uganda's political background and its current position in international development. How the findings address each of the four research questions is also addressed.

Chapter seven concludes by summarising the main findings and explains how these findings are relevant to informing and developing future policy to EVD and other epidemics. The implications of the study to the wider field of global health in terms of prevention, management and control of other diseases are described. The theoretical contribution of qualitative research and a critical anthropology to global health is rationalised. The limitations of the study are described and suggestions made for addressing them in future similar studies. Finally areas for further study are identified that can build on the findings from this study and address some of its limitations.

Chapter 2: Literature Review

2.1 Introduction

The literature review provides a critical in-depth background of what is known about the issue of interest. The literature review for this study became an iterative process that can be better described as cyclical rather than a linear construct within the thesis. At the proposal stage in 2013 where an overview of the extant literature was conducted, the researcher initially focused on providing a background to the study. Since then the researcher's experience, familiarity with the data and the unprecedented EVD outbreak in West Africa that took place parallel to this study provided additional material and concepts that helped to support the review. The discussion chapter (Chapter six) flows back and forth between the concepts highlighted in the literature review and the research findings.

2.2 Search Strategy for the Literature Review

The methodology used for identifying relevant literature began by examining the topic under study, more specifically by identifying components within the main objective or research question outlined in chapter one (section 1.4).

To understand the contexts from where two Ebola outbreaks emerged in western Uganda in 2007 and 2012, and how these outbreaks and the external interventions towards them were locally understood, experienced, and globally determined.

Once identified the individual components were explored further using keywords, phrases, and synonyms. The first main component in the research question was “*the contexts [...] in western Uganda*”. Key search phrases included: ‘geographical context of Western Uganda’, ‘cultural context of Western Uganda’, ‘socioeconomic context of Western Uganda’, ‘historical context of Western Uganda’, ‘political context of Western Uganda’. Synonyms or alternative phrases for ‘Western Uganda’ included ‘Uganda’, ‘Bundibugyo’, ‘Kibaale’, ‘East Africa’, and ‘The Great Lakes region’.

The second main component of the research question was “*Ebola outbreaks*”. Keywords phrases and synonyms here included ‘Ebola virus outbreaks in Uganda’, ‘Ebola virus’, ‘Ebola Hemorrhagic Virus’ (EHV), ‘Ebola Virus Disease’ (EVD), Bundibugyo virus, ‘*Bundibugyo ebolavirus*’, Sudan virus, ‘*Sudan ebolavirus*’. The third main component

identified within the topic of study was “*external interventions*” and “*globally determined*” which focused the search on ‘international health’, ‘global health policy’, ‘international responses to Ebola outbreaks’, ‘global health security’, ‘global health leadership’, ‘zoonotic disease emergence’ ‘emerging infectious diseases’, ‘geopolitics of Ebola’, ‘Ebola and foreign policy’, ‘Ebola outbreak AND West-Africa’ and ‘One Health’. The last component ‘*locally interpreted and experienced*’ led to exploring material under the phrases of ‘lived experiences of Ebola’, ‘Ebola AND Phenomenology’, local experiences AND Ebola outbreaks’, ‘Ebola AND fear’ and ‘Ebola AND stigma’. This was the area with the least available literature, identified as a gap and a main justification for the study.

Much of the literature review was internet-based using Trinity College Dublin (TCD) library electronic resources (www.tcd.ie/Library) and multiple other on-line data-bases including Google scholar, CINAHL, Ovid and PubMed MEDLINE and Scopus. Material accessed included literature from the disciplines of infectious diseases, health policy, global health, One Health, social science, political science, medical and critical anthropology of disease. Database searches used the Boolean operators, AND, OR, NOT to narrow and broaden searches. WHO reports, masters dissertations and doctoral thesis were also accessed from on line sources. The review also sourced material from non-internet based resources including print books, newspaper articles from the popular Ugandan and East African press. These included the *New Vision*, *the Observer*, *the Monitor*, and the *East African* tabloids. The researcher also attended four international conferences and one East/Central African workshop during the study period. The themes of these events focused on emerging infectious diseases, One Health, global health security and ‘anthropology and crises’.

Once identified, the headings and/or abstracts of articles were read to examine their relevance to the study and selection criteria guided further reading and analysis. Subject matter to be included as relevant included background to the clinical, epidemiological, geographical, cultural, socio-economic, historical, and political contexts of EVD outbreaks in Africa, particularly in Uganda. Historical accounts of previous outbreaks were included as many of these identified the perspectives from which they were narrated and concepts such as ‘emerging infectious disease’, ‘local’ versus ‘global’, ‘global health security’ and ‘One Health’.

Apart from a brief description towards recent advancements in treatments (Section 2.4.8.2), scientific articles relating to molecular biology research, clinical trial research, immunology, and vaccine development studies were excluded from the study.

Following the selection process, the content of articles were analysed in terms of their value to the study objectives. Relevant material was then summarised and categorised within five main sections that provided a background for discussion of the study findings. These five background sections include Uganda's Political History, Ebola Virus Disease, Cultural and Social Determinants of Disease, the Geopolitics of EVD and Local Experiences of EVD.

2.3 Uganda's Political History

This section provides a summary of Uganda's political background to convey the historical and contemporary political contexts from where the two EVD outbreaks emerged. It provides a summary of the various systems of governance experienced by the Ugandan people from authoritarian kinships to colonial rule, post-Cold War independence marked by dictatorships and violent conflict towards relative stability, democratization within an expansion era of international 'development' directed under neoliberal policies and global capitalism. More specifically it provides a broad background of the conflict in eastern DRC and the issue of the 'lost counties' relevant to the current political context of the two case study sites.

2.3.1 Clans, Kinships & Ethnic Divides

Uganda lies within what some authors refer to as the Great Lakes Region where centuries of migratory movements, environmental management and agro-pastoral systems between the first millennium B.C and the sixteenth century created diverse groups of settlers (Chrétien, 2006). In Uganda, clans remain the fundamental social identity where there are no less than forty clan networks, sub-divided into sub-clans and lineages. Each subdivision is hierarchically characterised into elder and younger lines. Clans form the oldest structure of society combining kinship, exogamy, shared symbols, and rules of solidarity (Chrétien, 2006). As clans dispersed across the region, lineages divided and increasingly political order intervened in the form of kingdoms during the eighteenth and nineteenth century (Chrétien, 2006, p. 95). Kingdoms in Uganda represented medium sized empires that established the political culture and held absolute fiscal and military power over their territories and subjects.

Colonial rule followed the arrival of European missionaries and explorers in the mid-nineteenth century. Explorers such as Speke (1863) put forward Eurocentric theories about

how the kingships had evolved in the region and hypothesised that a ‘civilised’ Hamitic or ancient Caucasoid race of Ethiopia descended on the Cwezi population through invasions from the north. Support for this racial theory from certain groups created a Hima –Iru rivalry in the region that has remained relevant up to contemporary times in terms of real or perceived ethnic divides. Archeological history however posits that a major ecological crisis such as drought destabilised the region at the turn of the sixteenth century and created divides that were socio-political rather than of racial origin (Chrétien, 2006). Bantu and Nilotic speaking groups divide Uganda linguistically from north to south.

2.3.2 Colonialism and Post Independence

Colonial rule in the region followed the arrival of European missionaries and explorers in the mid-nineteenth century. Colonialism has been described as the development of institutions and policies by Euro-American sovereigns towards indigenous populations beginning as a process of religious and secular rationalisations followed by the dispossession of land ownership for the exploitation of natural resources (Taiiaki G., 2009). According to Rotman (1996) colonialism aimed at ‘civilising’ the indigenous population through religious instruction and trades education. Uganda was colonised for 67 years between 1894 and 1961. The process began in 1893 when the Imperial British East African Company (IBEAC) transferred its administration to the British government and extended its area of control to approximately what corresponds to present day Uganda. Under colonialism, Uganda held a degree of self-governance as a British Protectorate administered through the Buganda tribe of Central Uganda. Some authors claim that the basis to understanding ethnic marginalisation in post-colonial Uganda derives from this ‘divide and rule’ method under British colonialism (Blanton *et al.*, 2001; Tornberg, 2012). While colonialism did favour certain ethnic groups above others and may be among the determinants that contributed to post-colonial ethnic fragmentation, it would be an oversimplification to assume it was the founding factor. The historical basis for contemporary political systems, structures and processes in Africa and the norms, rules and traditions that underpin them are rooted in a much more diverse socio-political context (Sesay, 2014). Despite a paucity of written documentation, the social and political history of this region began long before the period of European colonialism.

Uganda’s struggle for nationalism first emerged in 1952 with the formation of the Uganda National Congress (UNC). The Buganda royalists headed by their monarch, Kabaka

Mutesa II assumed that following the independence of African states they, as the dominant Ugandan political class would assume power. However, during the colonial period the Ganda society itself experienced internal conflict through religious differences in the form of a cleavage between Catholic and Protestant and to a lesser extent Traditionalist and Muslim divisions. In the period entering independence, Ganda Catholics were omitted from the political process through sectarianism and this resulted in a split in the UNC. Under the leadership of Apollo Milton Obote, a national coalition known as the Uganda People's Congress (UPC) was established that opposed the Baganda claim to power as a perceived continuation of colonialism. In 1964, the UPC won absolute majority and under Obote reinforced control over the army, who were predominantly made up of the Lango and Acholi ethnic groups from northern Uganda. In 1966 Obote, a socialist suspended the Ugandan constitution, abolished the monarchs, and proclaimed himself President. In 1971, a coup d'état orchestrated by Idi Amin and supported by the West deposed Obote. However, the period under Amin saw a continuation of Obote's dictatorship style of leadership with the expulsion of the Asian community, introduction of Islamic excess, executions, tortures, and economic collapse. The Tanzanian military and Ugandan exiles intervened and overthrew Amin in 1979 and Obote returned to power in 1980 by a contentious election process. Opposition to his reinstatement resulted in a guerrilla war headed by Yoweri Museveni's National Resistance Army (NRA) and other military groups. For Uganda's the transition from post independence military dictatorship to multiparty democracy transpired following five years of violent civil war known as the 'Bush War'. In 1986, Yoweri Museveni took power and created a united front with the Buganda and the western Bantu-speaking groups. From then, the country transitioned under a multiparty political system and President Museveni was re-elected in 2005, 2011, and more contentiously in 2016. In summary Uganda has never witnessed a peaceful transition in power since independence. For those who remember the days of Milton Obote, Idi Amin, and the subsequent Bush War, the political stability provided under the current presidency of Yoweri Museveni is mostly tolerated. For many among an educated growing middle class and an exponentially growing population of unemployed youth the post independence period of dictatorship, conflict and economic turmoil are not enshrined in their memories and change in leadership is perceived as long overdue.

2.3.3 Neocolonialism & International Development

Uganda's position in the global development discourse over the past 25 years can be divided into periods defined by colonialism, post independence cold war politics, and democratisation. During the cold war period, undemocratic government systems in the form of military dictatorships were in the majority across Africa. These were mostly tolerated and in many cases supported by western powers whose main priority leaned towards winning loyalty to African states against the Soviet Union (Sesay, 2014). As outlined above this period included almost twenty years of brutal and oppressive dictatorships experienced by the Ugandan people under Milton Obote (1966-1971; 1980-1985) and Idi Amin (1971-1979).

The end of the cold war marked by the fall of the Berlin wall in October 1989 saw civil society and political actors pushing for democratisation across Africa (Sesay, 2014). However, the transition from military dictatorship to 'democracy' as evidenced by Uganda's Bush War often came in the form of violent civil wars. This was a feature across the continent including prolonged civil wars experienced in Liberia, Sierra Leone, and the DRC.

In post-independent Africa, the role of western nations continued in the form of 'development partners' who supported the shift towards democratic political reform, even enforcing it through conditionality in exchange for foreign aid, grants and technical assistance. Political conditions were aggressively advocated, funded, and monitored by western dominated financial institutions, namely the International Monetary Fund (IMF), the World Bank and bilateral donors. The ending of the Cold War saw the introduction of an economic liberalization agenda where post-colonial sub-Saharan African economies were structured to meet the demands of industrialized Europe through the export of cheap raw materials (Carmody, 2011). Nkrumah (1966) referred to the situation where the rules dictating 'independent' African economies as a continuity of imperialism that replaced colonialism as 'neo-colonialism'. Similar to what Taiiaki describes as 'notions of superiority and divine rights to domination' such capitalist policies imposed on independent African states have remained largely unchanged since the colonial era. In the 1990's these neo-colonial policies were imposed on Africa in the form of structural adjustment programmes (Carmody, 2011). During that same decade average incomes across sub-Saharan Africa fell by twenty per cent leaving the average person poorer than they were in the 1970's and the 1960's with over 50 per cent of the population earning less

than USD\$1 per day (Harrison, 2010). This also represented the period when the HIV/AIDS pandemic exploded across sub-Saharan Africa. Carmody (2011) critiques this mode of 'economic development' as enforcing a global capitalist system with aid employed as a tool to corrupt political elites, distort trade and create a dependency culture that continues up to today. This capitalist expansion era has been critiqued as guiding a second scramble for Africa's natural resources to generate profits for global corporations (Taiaiake, 2009; Carmody, 2011). The power structures underlying colonial aspirations have reformulated behind a façade of neo-colonialism and international development that determine some of the same inequalities that exist today. Contemporary Uganda exists within such a liberalised economic structure where basic household necessities including water, health, primary, and secondary school education are borne by individual households. The destruction of lives because of the impacts of global capitalist expansion on an indigenous population can be best illustrated by the experiences of those living within the borders of the eastern DRC particularly over the past twenty years.

2.3.4 Uganda and Eastern Democratic Republic of the Congo

Chrétien (2006, p.9) argues that colonial partition in the Great Lakes region divided scholarship as much as politics into French-Belgian and English strands of research. Revolts that broke out in the mountains between Uganda and Rwanda in the twentieth century gave rise to accounts from both sides as if they were unrelated events. In the same way, to discuss the historical and political background of western Uganda without considering eastern DRC as part of the same region, the same people sharing the same culture is a misrepresentation. On going wars, violence and human rights violations in eastern DRC originate in a long history of control over land and natural resources by local and regional actors and their external supporters (Chrétien, 2006, Huggins *et al.* 2005).

2.3.4.1 The Congo Wars 1994 -2003

Most international reports and academic literature use the term 'conflict' in relation to events that have killed and displaced millions of civilians from the DRC over the past two decades. Less common in both the popular and academic literature are the 'local' terms used to describe events that took place between 1994 and 2003. The period between 1994

and 1998 is locally referred to as the ‘Banyamulenge uprising’, ‘the war of liberation’, the *Alliance des Forces Democratique pour la Liberation* (AFDL) offensive’ or more commonly the First Congo War. The period between 1998 and 2003 is referred to ‘locally’ as the Second Congo War or sometimes as the *Great African War* because of its magnitude and the involvement of nine African countries (Van Reybrouch, 2014).

The term ‘conflict’ commonly used in western popular literature to describe wars in and between African states derives from the Latin term meaning ‘to clash or engage in a fight’. The term ‘war’ is defined as ‘a state of armed conflict between different countries or different groups within a country’ (Moseley, 2007). Conflicts can be defined using quantitative measurements and battle related deaths above 1,000 per year constitute a war. Between 2.5 and 5 million was given as an estimated death toll in the DRC between 1996 and 2003 (Brennan *et al.*, 2006; Coghlan *et al.*, 2006; Spagat *et al.*, 2009). However, the true figures may never be objectively measured. For the purpose of this study, the term ‘war’ is used to describe events neighbouring western Uganda over the past two decades.

Although the second Congo war ‘officially’ ended in 2003 with foreign troops leaving, an unofficial war with numerous local militias (supported by foreign governments) continues up to the time of writing.

The first Congo war came in the aftermath of the 1994 genocide in Rwanda. North Kivu was home to the Banyarwanda (mostly Tutsi) who settled here following previous genocide during the Hutu uprising in Rwanda between 1959 and 1962. The Banyarwanda were awarded Zairean nationality and had the support of the long standing President Mobutu. However, in the early 1990’s local conflict arose between Zairian ‘nationalists’ and Tutsi settlers over land occupancy in eastern Zaire, one of Africa’s most densely inhabited agricultural regions. Local Zairians believed that the Tutsi firmly intended to annex North and South Kivu with Rwanda. In 1990, the Rwanda Patriotic Front (RPF) entered Rwanda from their base in Uganda in a civil war against the Hutu regime between 1990 and 1994. In 1993 between 4,000 and 20,000 Banyarwanda were killed in a war of ethnic cleansing against the Tutsi in North Kivu. In South Kivu, ethnic identification also became an issue. On 6th April 1994 following the shooting down of the plane of the Hutu President, Juvenal Habyarimana the genocide against the Tutsi began in Rwanda and within three months between 800,000 and 1 million Rwandans were killed. Following the death of 10 Belgian UN soldiers at the start of the Rwandan genocide the world turned away. The United States disengaged support, influenced by events in Somalia (Stewart,

2003). French President Francois Mitterrand supported the Hutu regime and facilitated Hutu refugees to flee into eastern Zaire. Mobutu won favour back in the eyes of the West for hosting 1.5 million refugees in North and South Kivu. However, Mobutu's Zaire was an absentee state at that time with a failed economy, a dysfunctional army, and an overpopulated eastern region already hostile to Rwandans. Following the genocide the leader of the RPF, Paul Kagame took control of Kigali but felt threatened by the 1.5 -2 million predominantly Hutu refugees including Hutu militia in eastern Zaire. Invading Zaire would mean invading a sovereign state so under the guise of a domestic uprising the AFDL was formed. Training of Zairian troops took place in Rwanda. With support from Uganda's president Yoweri Museveni and logistical and military support from the Clinton administration Zaire was occupied (Prunier, 1995; Prunier G., 2009; Cooper, 2013). The three main cities in eastern Zaire, Goma, Uvira, and Buhavu hosting the three main Hutu refugee camps were invaded first. Hundreds of thousands of refugees were killed and many more as the AFDL advanced to Kinshasa. The AFDL occupied Kinshasa on May 1997 and Laurent Desire Kabila was sworn in as president in the presence of his supporters, Paul Kagame and Yoweri Museveni. Mobutu exiled to Morocco where he died in September 1997. However, the new President turned his back on Rwanda and Uganda within one year of his presidency and requested foreign soldiers to leave their national territory (Strachan, 2004).

On 2nd August 1998, the second Congo war began. This time the rebel movement constructed by the Rwandan and Ugandan forces was called the RCD (*Rassemblement Congolais pour la Democratie*). This war was divided into three phases. From August 1998 to July 1999, the Ugandan and Rwandan forces tried to overthrow Kabila. However, support came from Zimbabwe and Angola followed by Namibia, Sudan, Chad, and Libya who were protecting their economic interests in the region. This phase ended with the Lusaka Peace Agreement. A second phase between July 1999 and December 2002 involved Rwandan and Ugandan occupancy limited to the eastern half of the country. During this period, Rwanda and Uganda engaged in conflict with each other over the mineral rich territory, particularly the diamond rich city of Kisangani. *Mission de l'Organisation des Nations Unites au Congo* (MONOC) entered the area for peacekeeping purposes in 2000 (UN Resolution 1279, 1999). This phase ended with the Pretoria Peace Agreement and Rwanda and Uganda withdrew their forces as the UN increased its presence (Van Reybrouck, 2014). This marked an 'official' ending of the war, but unofficially the war is fought in the extreme east of the DRC (North and South Kivu)

where massive human rights violations, extreme violence and human suffering continue up to the time of writing.

The Ugandan forces mainly controlled North Kivu and the majority of refugees in western Uganda originate from there (UNHCR, 2014). A failed economy in eastern DRC became a military economy. A war constructed to feed regional and global market demands became a full time economy for millions of unemployed youth in the region. For millions of others disease, death, and suffering became their reality.

“The ethnic violence in Ituri (eastern Congo) was no atavism, no primitive reflex, but the logical result of the scarcity of land in a wartime economy in the service of globalization – and in that sense, a foreshadowing of what is in store for an overpopulated planet. Congo does not lag behind the course of history, but runs out in front” (Van Reybrouck, 2014, 471).

Before the civil war that erupted in South Sudan in 2013, Congolese refugees represented over 65% of the total refugee population in Uganda (UNHCR, 2013). In 2012, 45,854 refugees were newly registered in Uganda originating from eastern DRC (UNHCR, 2014). Most of these are of Rwandan background referred to collectively as Banyarwanda. In Uganda, most Congolese refugees live in settlements to encourage integration, as repatriation to their homeland in North and South Kivu is not yet a viable option. However, competition over land and fishing territory has frequently caused clashes between refugee settlers and host communities. The Ugandan government has relocated many of the more recent refugee settlers to inland areas in Bundibugyo and Kibaale districts where they are given small plots of land to cultivate (McKinsey & Redmond, 2006). Since the civil war broke out in South Sudan in December 2013 the number of refugees and asylum seekers in Uganda by the end of May 2017 was over one million (UNHCR, 2017).

2.3.4.2 The Lost Counties

The three counties within Kibaale district are referred to as the “Lost Counties”(Espeland, 2006). During colonialism, the British granted large tracts of titled land in western Uganda (originally part of the Bunyoro Kingdom of which Kibaale belonged to) to the administrative elite in the Buganda Kingdom under the 1900 Uganda Agreement. This reflected favouritism by the colonialists for their Buganda allies prolonging an ancient

rivalry that existed between the kingdoms of Buganda and Bunyoro. Up to the time of data collection, the 'lost counties' issue frequently results in contentious ethno-political events that surface in Kibaale and the surrounding districts. Kibaale district does not have the same level of conflict as experienced in Bundibugyo district but it does host refugees from DRC and is not completely immune from instability.

2.4 Ebola Virus Disease

This section of the literature review focuses on the virus and the disease from an epidemiological and clinical perspective.

As outlined in chapter one the term Ebola Virus Disease (EVD) has more recently replaced the original term Ebola Haemorrhagic Virus (EHV) as it is now recognized that the haemorrhagic symptoms associated with the virus are not as major a clinical manifestation as previously perceived (Kortepeter *et al.*, 2011). This change in terminology emerged in the scientific literature associated with the recent West African outbreak (2013 -2016) as more evidence documenting case presentations were generated. It is now recognised that EVD only presents with haemorrhagic symptoms in less than 7% of cases and usually towards the terminal stages of the disease (Bray *et al.*, 2015a). A figure of 20% is likely to include both major and minor haemorrhagic symptoms. As outlined below in section 2.4.3, haemorrhagic symptoms were previously misrepresented as the most common clinical presentation of the disease.

The change in terminology to EVD from EHV is interesting and questions how much the original title derived from evidence-based research versus popularised public perception in western media.

2.4.1 Epidemiology

EVD is caused by *Ebolavirus*, a genus belonging to the family of virus known as the Filoviridae shared with two other genera; *Marburgvirus* comprising various strains of the *Lake Victoria marburgvirus*, (Towner *et al.*, 2009) and a more recently discovered filovirus, *Lloviu virus* (Negredo *et al.*, 2011). This more recently discovered filovirus was isolated from insectivorous bat die-offs collected from caves in northern Spain between

2004 and 2008 but is non pathogenic to humans. This was the first filovirus detected in Europe not imported from an endemic area in Africa (Negredo *et al.*, 2011). Ebola and Marburg viruses are amongst the most lethal of primate pathogens reported as natural infections in sub-Saharan Africa and the Philippines. The Filovirus family were first identified under laboratory conditions in 1967 when dissection of monkeys imported into Marburg, Germany from Uganda resulted in severe morbidity among plant workers using kidney cell cultures for polio vaccine production (Martini, 1969).

To date five species of the *Ebolavirus* genus have been identified comprising *Zaire ebolavirus*, *Sudan ebolavirus*, *Tai Forest ebolavirus* (formerly Côte d'Ivoire), *Reston ebolavirus*, and *Bundibugyo ebolavirus* (Towner *et al.*, 2008).

In 1976, the first documented record of an EVD outbreak appeared in western literature when two outbreaks occurred almost simultaneously in South Sudan (formerly Sudan) and the DRC (formerly Zaire). However recent studies on virus genetic diversity detected in bat populations suggest that virus within the *Marburg virus* and *Sudan ebolavirus* species date back 750 to 800 years (Carroll *et al.*, 2013). These findings are interesting in that they support the theory that Ebola viruses have been historically described in areas now known to be endemic across sub-Saharan Africa (Hewlett & Hewlett, 2008).

2.4.1.1 A Natural Host

Zaire ebolavirus has been isolated from fruit bats of the *Pteropodidae* family. Species including *Hypsignathus monstrosus*, *Epomops franqueti* and *Myonycteris torquata* are considered natural hosts of the virus but are asymptomatic and other mammals and humans are considered accidental hosts (Leroy *et al.*, 2005). Rouquet *et al.* (2005) suggested that humans did not seem to be at a major risk of infection from the natural host. However, this observation may have been premature due to a lack of research at that time. In 2011 an epidemiological investigation of a single case fatality concerning an eleven-year old girl in Luweero district, central Uganda did not reveal any contact with a potential animal reservoir. Natural host infection was suspected as several bat species were found in the immediate environment (Shoemaker *et al.*, 2012).

2.4.1.2 Outbreaks among Wildlife

The first recorded case of EVD among non-human primates was identified in laboratory monkeys in the USA in 1989 (Jahrling *et al.*, 1990). This newly identified enzootic virus sub-type; *Reston virus* (RESTV) occurred again among monkey colonies in US laboratories in 1990 and in a laboratory in Italy in 1992. The source of these outbreaks originated from a breeding farm in the Philippines (Jahrling *et al.*, 1990). In 1994, the first Ebola outbreak in nature was described among a wild chimpanzee community in the Tai Forest National Park in Cote d'Ivoire (Formenty *et al.*, 1999). Colobus monkeys were suspected as an intermediate host in this case but the natural host was not identified. Ebola epidemics and their impact among gorilla and chimpanzee populations are well documented in equatorial Africa (Formenty *et al.*, 1999; Leroy *et al.*, 2004; Rouquet *et al.*, 2005, Huijbregts *et al.*, 2003; Walsh *et al.*, 2003, Devos *et al.*, 2008). Primologist studies between 1998 and 2000 in North-eastern Gabon revealed that the population of gorillas and chimpanzees dramatically decreased by over 90% when compared with previous nest counts undertaken in 1994 (Kuhn *et al.*, 2008). A second study in Gabon shows that the population of the great apes decreased by more than 56% between 1983 and 2000 (Walsh *et al.*, 2003). One argument is that human activities, mainly logging and hunting are underlying factors for the decline but it is also argued that an increased prevalence of EVD maybe responsible. It is feasible to consider that human activities within the area are resulting in displacing the population of animals into smaller habitats where they are more susceptible to the virus because of stress and increased contact with the natural host and each other. In one study, close contact was identified as a risk factor among lowland gorillas, where contact between individuals within a group strongly influenced the spread of infection compared with solitary gorillas (Caillard *et al.*, 2006). The most vulnerable position among social gorilla groups was between a lactating mother and her infant (Caillard *et al.*, 2006). A deeper exploration of plausible underlying determinants is scant within the literature.

An interesting feature arising from the studies related to outbreaks among wildlife populations is that species other than primates were infected. Using reverse transcriptase (RT)-PCR, the Gabon study was the first to identify the duiker or small forest dwelling antelope (*Cephalophus dorsalis*) as an intermediate mammalian reservoir for filoviruses. Before this study, only chimpanzees and apes were considered in previous outbreaks. Unpublished research conveyed that whilst the duiker is primarily herbivorous, they have been known to lick decomposing carcasses (Abernethy, unpub. data). In 2008, Reston

virus species *Reston ebolavirus* was identified in domestic pigs (WHO, 2009). *Reston virus* is known to infect multiple species, including humans and because of this, virus transfer between species continues to be epidemiologically investigated between public health and veterinary agencies (Miranda & Miranda, 2011).

2.4.1.3 Zoonosis

Most human outbreaks to date have emerged from a single case known as an index case. This is usually associated with a history of direct human contact with an infected animal through hunting or consumption of meat from an infected wild animal known as zoonotic transmission. Five Ebola outbreaks that occurred over an area transcending north eastern Gabon and north western Republic of Congo between 2001 and 2003 revealed that 13 human index cases were due to confirmed or suspected consumption of gorilla, chimpanzee or duiker carcass (Rouquet, 2005). *Reston virus* was identified coincidentally in pig tissue samples sent to the USA by PCR, during epidemiological investigations of a Porcine Reproductive and Respiratory Syndrome (PRRS) outbreak in the Philippines in 2008 (Miranda & Miranda, 2011). Evidence that zoonotic transmission between pigs and humans was confirmed when six individuals who had daily occupational contact with pigs tested positive for Immunoglobulin G (IgG) antibodies for RESTV (WHO, 2009). This finding was significant because it demonstrated the transfer of Ebola virus from a natural host or an infected wild animal source to domestic animals and subsequently from domestic animals to humans through contact. Although IgG antibodies for RESTV were identified in laboratory personnel in Italy and the USA, none of the cases resulted in human disease and to date *Reston virus* is not known to be pathogenic to humans (WHO, 1992; WHO, 2009).

2.4.1.4 Human-to-Human Transmission

Following an index, transmission event the most common subsequent mode of transmission in epidemics documented to date is human to human. Ebola virus transmission between humans is well documented and occurs through close contact with blood and other bodily fluids of another infected person directly or indirectly through a contaminated environment (Bausch *et al.*, 2007, Francesconi *et al.*, 2003). In a study in

Conakry Guinea in 2014, 62% of infection was introduced through ‘household clustering’ (Bah *et al.*, 2015). Ebola virus has also been isolated from human breast milk up to 16 months post infection (Moreau *et al.*, 2015). Recent studies have also found that sexual transmission of EVD has occurred nine months after an infected person has been announced virus free (WHO, 2014b).

However, the most common mode of transmission among humans is nosocomial transmission that has been shown to amplify in resource poor settings. Health care facilities managing outbreaks in these contexts have been well documented throughout the history of EVD outbreaks as places where transmission from patient to patient and from patient to health care personnel has occurred (WHO, 1978; Baron *et al.*, 1983; Bah *et al.*, 2015; Borchert *et al.*, 2011). This has also resulted in fear among patients to seek admission to Ebola units and fear among staff to continue working in health facilities where Ebola cases have been admitted, particularly where adequate resources for their personal protection and general infection control are not available (Kinsman, 2012, Rico *et al.*, 2016). Before the West African outbreak, all recorded cases beyond the African continent (USA, UK, Italy, Germany and Russia) resulted from accidental infection within military research laboratories and vaccine production plants (Emond *et al.*, 1977; CDC, 1989; International Society for Infectious Diseases, 2004; 2009). More recently, Ebola transmissions beyond the African continent (USA, Spain, Italy and the UK) were recorded among health care workers who became infected when treating patients and were medically evacuated from West Africa (Warrick, 2014; Lyon *et al.*, 2014; Uyeki *et al.*, 2016).

2.4.2 Case Fatality Rates

Case fatality rate (CFR) is defined as the ratio of cumulative fatalities to the cumulative cases confirmed (CDC, 2014). The range of case fatality rates has been reported to vary considerably between EVD patients from 25 – 90%. Multiple factors in addition to the virulence of the virus subtype are responsible for this variation (WHO, 2017). These factors include age, the stage of the disease when diagnosed, initiation of treatment following symptoms, the type and availability of critical care treatment, capacity to monitor and respond to the status of patients blood biochemistry and the age and immune status of the patient (Aylward *et al.*, 2014).

Ebola Zaire is documented as having the highest case fatality rate, up to 90%, suggesting that this is the most virulent strain (Bray *et al.* 2015). Consideration also needs to be given

to the fact that areas where outbreaks of *Zaire ebolavirus* (EBOV) species have occurred in the past are among the poorest countries in the world as outlined in chapter one (Table 1.3). The case fatality rate recorded in the West African outbreak varied from between 18% to 70% (Alyward *et al.*, 2014, Yamin *et al.*, 2015). One epidemiological study of patients treated at a specialised Ebola Treatment Centre (ETC) in Conakry, Guinea supported by international organisations had a reported case fatality rate of 41% (Rico *et al.*, 2016). Another study of patients who were medically evacuated out of West Africa to the USA and Europe for critical care treatment reported to have a case fatality rate of 18%. Therefore it could be argued that case fatality rate is more strongly correlated with context in terms of access to appropriate treatment rather than the virulence of the disease strain (Uyeki *et al.*, 2016).

2.4.3 Clinical Manifestations in Humans

Initial clinical manifestations of EVD are non-specific and appear similar to other common acute febrile illnesses such as malaria and typhoid (Okware *et al.*, 2002). The incubation period for EVD ranges between two and 21 days and patients are not considered infectious until they develop clinical features (Bray *et al.*, 2015). The most common documented clinical signs are fever, lethargy, abdominal pain, vomiting, and diarrhoea (Kortepeter *et al.*, 2011; Bwaka *et al.*, 1999; Formenty *et al.*, 1999, Lyon *et al.*, 2014).

A retrospective observational cohort study using statistical analysis for over a one month period in Conakry, Guinea during the West African Ebola outbreak revealed that 84% of suspected and laboratory confirmed patients presented with fever, 65% with intense fatigue, 62% with diarrhoea, 57% with vomiting, 57% with headache and 28% with hiccups. In this study, a 43% mortality rate was reported because of hypovolaemic shock despite some intravenous fluid therapy (Bah *et al.*, 2015). Another epidemiological study in Conakry and surrounding prefectures reported the most common presenting clinical features at Ebola Treatment Centres (ETC's) at 96% was fever, 96% fatigue and 86% inappetance (Rico *et al.*, 2016). The mean time from onset to presentation of clinical features was five days and from presentation to death was eight days. Clinical features were similar to an earlier study done in Masindi District, Uganda in 2011 where 88% of laboratory confirmed cases presented with fever, 88% with loss of appetite, 75% with intense fatigue, and 71% with headache. Clinical manifestations in a study of 27 patients treated in Europe and the USA reveal that among the most common presenting clinical

features were fatigue at 80% and fever at 68%. Blood haematology and biochemical features among patients with severe diarrhoea and vomiting include an abnormal haematocrit, leucopenia, thrombocytopenia, elevated liver and kidney enzymes, hypo or hyperkalaemia, hyponatremia, hypocalcaemia and hypoproteinaemia. These features are associated with the pathogenesis of hypovolaemic shock as outlined below (Uyeki *et al.*, 2016).

Wamala *et al.* (2010) claim that approximately half of infected patients present with haemorrhagic features, however the supporting references lack validity. These include Okware *et al.* (2002) who refer to 30% of case descriptions as presenting with haemorrhagic symptoms in the Gulu outbreak in northern Uganda in 2000 but do not refer to the research supporting this claim. The second reference by Bwaka *et al.* (1999) refers to haemorrhagic features but on closer examination, these are minor manifestations. In comparison to clinical case studies by Bah *et al.* (2015) only 4.2 % of cases presented with haemorrhagic features at admission (Bitekyerezo *et al.*, 2002). These findings were similar to clinical case studies among patients in the USA and Europe that revealed only 7% of infected patients showing signs of major haemorrhage towards the terminal stage of the disease.

Reporting of haemorrhagic features, as a clinical manifestation of EVD could be better defined and classified into major and minor haemorrhagic manifestations. It is also important to acknowledge if reports of haemorrhagic features were conducted by clinical staff treating patients directly or if these reports were based on anecdotal sources. This is important, as major haemorrhage is frequently quoted as a clinical manifestation of EVD. If haemorrhagic features of EVD are over emphasized as a clinical presentation (as they have been up to 2014) this could lead to a misrepresentation as a symptom necessary for diagnosis and case definition. Lack of haemorrhagic symptoms have been claimed as a reason for misdiagnosis and delayed diagnosis in the past (Alsop, 2007; Mason, 2008). The impact of such misdiagnosis in terms of mortality and infection rates has not been measured.

The large number of case reports and patient series now available from the West African outbreak (2013 -2016) have raised two main distinctions with earlier interpretations of EVD. The first as outlined above refer to the haemorrhagic features of the virus being less prevalent a clinical manifestation than originally perceived and secondly that the contribution of hypovolaemia because of vomiting and diarrhoea is greater than previously reported (Bray *et al.*, 2015a). The importance of adequate fluid therapy during treatment

for hypovolaemic shock can result in reduced mortality of an infected patient. Fluid therapy particularly when accompanied by monitoring patient blood biochemistry is a cost effective means of treatment during Ebola outbreaks and may be undermined by donors in search of superior medico-technical interventions. This is discussed further in section 2.4.7.

Another clinical sign reported in case studies in the DRC, Côte d'Ivoire and the USA among infected health care workers not previously highlighted was the development of a diffuse, erythematous, non-pruritic macro-papular rash involving the upper body, particularly the face, neck, trunk and arms. The skin was likely to desquamate or lift from the epidermal layer (Kortepeter *et al.*, 2011; Bwaka *et al.*, 1999; Formenty *et al.*, 1999; Lyon *et al.*, 2014).

Other clinical manifestations reported throughout the literature include miscarriage (Jamieson *et al.*, 2014), uveitis (Kibadi *et al.*, 1999), neurological symptoms suggestive of meningoencephalitis (Kruels *et al.*, 2014), chest pain, dyspnoea and subconjunctival haemorrhage (Martini *et al.*, 1969).

A comprehensive review of clinical manifestations by Bray *et al.* (2015a) concludes that the clinical presentations highlighted in previous studies mostly refer to cases displaying severe clinical symptoms and may overlook milder or asymptomatic cases that may have gone undetected (Bellan *et al.*, 2014; Leroy *et al.*, 2000, Heffernan *et al.*, 2005). A single case fatality in Luwerro district in central Uganda in 2011 identified positive IgG antibodies in a blood sample taken from a juvenile relative of the deceased during follow up investigations (Shoemaker *et al.*, 2012). IgG antibodies indicate past infection of up to two years following infection (Ksiazek *et al.*, 1999). Previous studies in DRC, Gabon and the Central African Republic also provide evidence of asymptomatic infections to EBOV among humans (Leroy *et al.*, 2000; Gondalez *et al.*, 2000; Busico *et al.*, 1999; Bequart *et al.*, 2010). This conveys that humans can develop a strong inflammatory response towards infection and the true prevalence of the disease within human populations in endemic areas remains unknown.

Recovery from EVD can take up to two years for some patients and complications such as uveitis, neurological symptoms, and joint pains have been reported (Bwaka *et al.*, 1999; Kibadi *et al.*, 1999).

2.4.4 Clinical Manifestations in Animals

Clinical features among infected wildlife are similar to those of humans. An outbreak of *Ebola Reston* documented in monkeys in the USA in 1989 imported from the Philippines

reported severe diarrhoea (50%) and respiratory disease (34%). A case fatality rate of 82% was reported but the study did not report if any treatment intervention was delivered although this is unlikely. Elective euthanasia of confirmed cases was not reported. Haemorrhage was reported at 1%, (Miranda & Miranda, 2011). In the absence of treatment, fatality rates have been reported as high among wildlife populations as evidenced in the Gabon study (Kuhn *et al.*, 2008).

2.4.5 Pathogenesis

The pathogenesis outlines how the virus manifests inside the host either human or animal and brings about a disease state manifesting as the clinical symptoms described above. Tissue invasion by the virus occurs following infection from an infected animal or human through fluids passing through breaks in the skin or gut mucosa. Beeching *et al.* (2014) describes the pathogenesis of EVD predominantly in terms of the virus' ability to modulate cells involved in immune host response by multiplying within host cells and being transferred to the lymph nodes, liver, and spleen. He claims that it is the level of immune host response that dictates the outcome for the patient. The disease becomes severe when the virus triggers expression of a host of pro-inflammatory cytokines resulting in disseminated intravascular coagulopathy (DIC) and thrombocytopenia. In addition, hepatic impairment, severe kidney injury, and pancreatitis lead to haemorrhage and death (Beeching, Fenech & Houlihan, 2014). However, this conclusion arose from studies surrounding the pathogenesis of EVD done on non-human primates and rodents under laboratory conditions (Feldman *et al.*, 2011). In his study, Beeching claims that the pathogenesis of hypovolaemic shock in EVD is less understood and maybe due to multiple factors including bacterial sepsis or the direct affect of the virus, DIC or haemorrhage.

Bray *et al.* (2015a) on the other hand posits, using case studies from the West African outbreak, that hypovolaemic shock due to vomiting and diarrhoea makes a much greater contribution to mortality among infected patients than previously perceived (Schieffelin *et al.*, 2014; Lyon *et al.*, 2014; Chertow *et al.*, 2014; Bah *et al.*, 2015). He describes how some case series reported fluid losses of up to ten litres per day from infected patients through the gastro-intestinal tract (Lyon *et al.*, 2014).

Hypovolaemic shock results in intravascular volume depletion due to loss of blood volume indirectly because of prolonged vomiting and severe diarrhoea. In physiological terms hypovolaemic shock depletes blood volume as extracellular plasma moves into the

intracellular or tissue spaces. This reduces cardiac output resulting in low venous oxygen saturation and inadequate tissue perfusion. An anaerobic state in the tissues results in a metabolic acidosis and increased hydrogen ions are exchanged with potassium ions from the blood as the body attempts to maintain homeostasis. Increased potassium ions result in a condition referred to as hyperkaleamia resulting in pre renal kidney dysfunction, cardiac toxicity, and imminent death (Day, 2003). The pathogenesis of hypovolaemic shock is an identical physiological process for both humans and animals. For example canine, feline and swine parvovirus (a highly infectious haemorrhagic enteritis in dogs, cats and pigs) is commonly treated by veterinarians. The objective of treatment is to reverse the metabolic acidosis and buffer the hyperkaleamic state caused by the hypovolaemia through the provision of fluid therapy and electrolytes that indirectly support the body towards a state of homeostasis. An important component of treatment is monitoring blood biochemical parameters where blood analysis equipment is available. In a recent study in Conakry, Guinea the authors conclude that in addition to equipment for EVD diagnosis, basic inexpensive blood chemistry and hematology equipment are essential at treatment facilities to monitor patient biochemistry status, guide treatment and improve patient outcomes (Bah *et al.*, 2015).

2.4.6 Diagnosis

Initial diagnosis of EVD depends on clinical signs and patient symptoms within any given context. However as described above initial clinical manifestations are similar to several other endemic conditions presenting with fever, lethargy and gastro-intestinal disorders. Depending on the context, EVD may be considered within the preliminary list of differential diagnosis, particularly in areas where a history of the virus exists or during an outbreak. Differential diagnoses for EVD include malaria, typhoid, diphtheria, acute diarrhoea, flu, meningococcal disease, measles, and Marburg or Lassa virus endemic to West Africa. A confirmed diagnosis involves identifying specific RNA sequences using reverse-transcriptase polymerase chain reaction (rt-PCR) in patients at least three days from onset of symptoms. Laboratory diagnoses of antigens are done using immunoassays or nucleic acid testing. According to Bray *et al.* (2015) the sensitivity of rt-PCR diagnostics is required to confirm infection as genetic diversity and rapid accumulation of sequence changes have been demonstrated (Gire *et al.*, 2014). In the majority of resource, poor contexts where EVD outbreaks have occurred diagnostic equipment did not exist and

samples were referred to South Africa, Europe, or the United States. As outlined in section 2.4.3 above the importance of evidence-based clinical manifestations is highly important particularly in a resource poor context where a tentative diagnosis may be the only type of preliminary diagnosis available. This also requires a well-defined case definition in outbreak situations.

2.4.6.1 Case definition

A case definition is used during epidemics as a tool to facilitate epidemiological investigations and conduct rapid surveys. A case definition provides a standardised outline of, for example, the most common clinical symptoms that a patient with EVD would present with in the context of an Ebola outbreak. In Conakry, Guinea during the 2013-2016 West African outbreak a patient presenting with high temperature, lethargy, abdominal pain, vomiting and diarrhoea was highly suspected of having EVD (Rico *et al.*, 2016).

According to the CDC

“Development of a clear case definition is critical to effective investigation of an outbreak. Use of common case definition allows standardization of the cases of interest both within an outbreak investigation and possibly between outbreak investigations that differ over time or geographic location”. (CDC, 2002, p.1 [/www.cdc.gov/urdo/downloads/casedefinitions.pdf](http://www.cdc.gov/urdo/downloads/casedefinitions.pdf))

A case definition will be specific to the outbreak under investigation and includes criteria for person, place, time, and clinical manifestations. A further category common to case definitions in outbreaks is the level of certainty as confirmed, probable or suspected. WHO case definition of EVD falls under the three categories of suspected, probable or laboratory confirmed (Table 2.1). Laboratory analysis assists in arriving at a definitive diagnosis. In the case of EVD, confirmed cases are defined as those that test positive for the virus antigen in laboratory analysis. However as outlined above initial diagnosis in resource poor contexts relies on arriving at a tentative diagnosis based on a comprehensive history and clinical examination, as access to the diagnostic equipment required for novel viruses such as Ebola may not be immediately available.

Table 2.1: WHO Case Definition for Ebola Viral Disease in an Outbreak Setting

A suspect case is any person:

Having had contact with a clinical case (suspect, probable or confirmed)¹ AND

Presenting with acute fever (>38°C)

OR

Having had contact with a clinical case AND presenting with three or more of the symptoms below

OR

Presenting with acute fever AND presenting with three or more of the symptoms below:

Headache – abdominal pain – generalised or articular pain – difficulty in swallowing – intense fatigue – difficulty in breathing – nausea or vomiting – hiccups – loss of appetite – miscarriage – diarrhoea

OR

Any person with unexplained bleeding or miscarriage

OR

Any unexplained death.

A confirmed case is any suspect or probable case with a positive laboratory result. Laboratory confirmed cases must test positive for the virus antigen, either by detection of virus RNA by reverse transcriptase real time-polymerase chain reaction (rt-PCR), or by detection of IgM antibodies directed against Ebola, or viral isolation. A probable case is any suspected case evaluated by a clinician OR any deceased suspected case (where it has not been possible to collect specimens for laboratory confirmation) having an epidemiological link with a confirmed case.

Source: World Health Organisation (2014e)

2.4.7 Individual Patient Management

No specific effective drug is yet commercially available to treat Ebola but experimental drugs were provided to patients in the USA and Europe during the 2013 -2016 West African outbreak. Monoclonal anti-body based therapy (ZMapp) was given to two American health care workers who contracted the infection while treating patients in West Africa (Mishra, 2014). This innovative drug comprises of three ‘humanised’ monoclonal antibodies (MB-003) manufactured in the tobacco plant, *Nicotiane*. Both recipients of the drug survived but the author states that it cannot be confirmed whether it was the drug or access to high quality critical care treatment that was responsible for this outcome (Mishra, 2014). A more recent study reports on patients with EVD who were also treated in the USA and Europe during the West African outbreak (Uyeki *et al.*, 2016). These patients received comprehensive care including a combination of intravenous fluid hydration, correction of electrolyte abnormalities, parenteral nutritional support, and critical care

management including mechanical ventilation and renal replacement therapy. 85% and 70% respectively of these patients also received investigational and experimental therapy (Uyeki *et al.*, 2016). Mortality rates among these patients was 18% compared with West Africa where mortality rates among patients accessing specific Ebola treatment units (ETU) supported by international agencies were reported at 43% (Bah *et al.*, 2014). Less resourced areas among the five West African countries affected reported mortality rates above 86% (Baise *et al.*, 2014). In defense of the discrepancy between the outcomes in West Africa versus western countries, the author refers to the challenges of treating overwhelming numbers of patients in resource poor settings. A single case study in Luweero, central Uganda in 2011 presented at Bombo Military Hospital resulted in death three hours following admission with severe clinical symptoms. The patient had received mechanical ventilation but little else is reported in the literature in terms of any other treatment interventions (Shoemaker *et al.*, 2012). In fact, details of specific treatment interventions for clinical cases throughout the pre-West African literature are scarce. For example a comprehensive description of the largest reported outbreak in Gulu, northern Uganda in 2000 refers only to patient isolation, barrier nursing, contact tracing, infection control and waste management under case management but makes no reference to specific treatment protocols for individual patients (Okware *et al.*, 2002).

More available research on clinical case studies undertaken during the West African outbreak is valuable for their contribution to the understanding of effective treatment interventions. Observations from medical practitioners working in West Africa support the theory that intravenous fluid therapy is specific care for patients infected with EVD (Lamontague *et al.*, 2014). Intravenous fluid therapy for treating dehydration has a positive impact on case fatality rates. Treatment of patients with dehydration leading to hypovolaemic shock due to prolonged vomiting and diarrhoea is not a new phenomenon. As outlined above highlighting hypovolaemic shock, as a major cause of death in patients with EVD is important because fluid therapy and the consumables required to administer it are available, low cost and in most cases accessible in most resource poor settings. According to Kreuels *et al.* (2014) over ten litres of fluid replacement is needed for patients with hypovolaemic shock due to severe loss of fluid volume through vomiting, diarrhoea, and heat exchange. No studies exist that calculate the actual loss of body fluids through heat exchange in the sealed isolation tents used to isolate patients in the tropical climates where the majority of EVD outbreaks are managed.

As outlined in section 2.4.5 above the actual volume of intravenous fluids required to treat dehydration and hypovolemic shock should ideally be monitored on a patient's blood biochemistry status however such diagnostics, although inexpensive are not commonly available during EVD outbreaks. Oral rehydration fluids have been reported among some studies but are limited to patients who are not vomiting.

Previous studies describing outbreaks in the African context emphasized interventions around containment of EVD transmission and epidemiological investigation (Okware, 2002; Wamala, 2010, Shoemaker *et al.*, 2012). Several studies specific to treatment of patients infected with EVD in Europe and the USA were available in the literature (Lyon *et al.*, 2014; Uyeki *et al.*, 2016; Wolf *et al.*, 2015; Mora-Rillo *et al.*, 2015). As argued by Bah *et al.* (2015) association between treatments and outcomes in small observational studies are limited in the contribution they make to the evidence because selection of patients for certain treatment is subject to bias. For example in the USA and Europe critical patients not responding to intravenous fluids were also offered renal replacement therapy and in some cases platelet and plasma transfusions (Uyeki *et al.*, 2016). As mentioned above case fatality rates were 18% when compared with those in ETU's in West Africa where case fatality rates reported were between 43% (Uyeki *et al.* 2016) and 86% (Baise *et al.*, 2014).

In addition to fluid therapy, the literature revealed that gastrointestinal symptoms were routinely treated with antibiotics with activity against gram-negative, gram-positive, and anaerobic organisms (Kreules *et al.*, 2014; Bah *et al.*, 2015, Bray *et al.*, 2015). In the Conakry study, it was reported that antibiotics were administered empirically in 37 patients (100%) with gastrointestinal symptoms, and artemisin-based combination therapy was administered in seven patients (19%), four of whom, had confirmed *Plasmodium falciparum* infection on rapid diagnostic testing (Bah, 2015). One patient (3%) received supplemental oxygen therapy for hypoxemia. However, the effect of these interventions remains unknown (Bah, 2015).

From the researcher's experience in veterinary medicine, treatment of acute diarrhoea irrespective of the pathogen involved is aimed at correcting the resulting fluid and electrolyte deficits. In human medicine, treatment of hypovolaemic shock during cholera outbreaks is approached using aggressive fluid therapy. It is well recognised in veterinary medicine that antibiotics have little role in the treatment of diarrhoea and are even contraindicated where intestinal compromise is involved (Day, 2003). Antibiotics are usually only considered where blood sepsis is present. Over-prescribing antibiotics to

patients during epidemics may reflect certain desperation on the part of health care workers given the limited information and alternatives they have available. In addition, bacterial diarrhoea including typhoid and cholera are highly prevalent in these contexts.

2.4.8 Outbreak Management & Control

An area within the literature that is well documented is that of case management and control. Case management is based on rapid case ascertainment, isolation of patients and strict nursing barrier control. Active case findings and contact tracing of confirmed cases followed up with monitoring of all in-contacts for clinical features of EVD for 21 days is an essential and often challenging part of management. Two to twenty-one days represents the human incubation period between infection with the virus and presentation of clinical features of EVD. Previous Ebola outbreaks refer to surveillance, contact tracing and monitoring. As outlined above in section 2.4.1.4, in-contacts most at risk are those persons who are most susceptible to coming into contact with body fluids of a patient infected with the virus. These include health care workers, primary care givers at the patients' home, household contacts and infants being breast fed by an infected person. Persons involved in cleaning and embalming an infected body for burial in addition to those attending the burial are also at high risk of infection if they have been exposed to the body fluids of the deceased. Ensuring burial of Ebola deaths is safely implemented are essential activities in controlling Ebola outbreaks (Beeching, Fenech & Houlihan, 2014).

According to Bah *et al.* (2015) Guinea's capital, Conakry represented the first large urban outbreak of EVD. The author describes Conakry as a demonstration of how large urban settings present special challenges to health care facilities. However in East and Central African countries the majority of populations are rural based and where health facilities and human resources for health are scarce this means that those available are frequently struggling to function beyond their capacity. For example, over 85% of Uganda's population is rural based subsistence farmers who only have access to local public hospitals and health centres (UBOS, 2016).

2.4.8.1 WHO Model of Infection Control

The WHO biomedical model of infection control has five critical areas for implementing an effective system of infection prevention and control when caring for patients with suspected or confirmed Ebola within a health care setting (WHO, 2014g). These five areas include general patient care, direct patient care, waste management, environmental cleaning including linen and finally non-patient care activities including diagnostic laboratory procedures, post mortem, and management of human remains. The five areas comprise a number of activities, indications and techniques for each activity recommended to effectively implement the management of suspected and confirmed Ebola outbreaks in a health care setting (WHO, 2014g). Implementation of these activities assumes basic resources, systems and personnel capacity are available to manage an outbreak.

Unfortunately, many resource poor contexts in sub-Saharan Africa do not have the most basic resources including gloves, disposable needles, or disinfectant (Farmer, 1999).

2.4.8.2 Advances in Diagnostics, Treatment & Prevention

The West African outbreak EVD attracted much attention towards developing an Ebola prophylaxis and treatment. For example, a Google search using the term 'Ebola vaccine' brings up over 8 million articles. A *PubMed* search brings up over 800 scientific articles related to Ebola vaccines and treatments. Some novel advances in experimental treatment and medical interventions that arose during the West African outbreak are outlined.

ZMapp, a monoclonal antibody in addition to three other potential anti-Ebola drugs have been developed. SiRNA small interfering RNA molecules were reported to provide 100% protection thirty minutes post-infection. The drug has since been approved by the US Food and Drug Administration (FDA) for use in infected patients in the USA (Falzarano & Feldmann, 2014). Three drugs that inhibit viral replication have also been identified as potential treatments for EVD. These include PMO Plus (Positively charged phosphorodiamidatemorpolino oligomers), BCV4430 anadenosine analogue, and T-705 (favipiravir) a pyrazinecarboxamide derivative (Warren *et al.*, 2010; Falzarno & Feldmann, 2014).

Rapid antigen tests for diagnosing the virus under field conditions have also been developed with high sensitivity, but specificity is only around 92%. These tests can

provide a result in 15 minutes but require RT-PCR backup for a confirmed diagnosis (Broadhurst *et al.*, 2015). In Nigeria an mHealth innovation was described in a recent study where a mobile phone tutorial application was used as a health promotion device to ‘change knowledge and attitudes’ of frontline health care workers around risk factors associated with Ebola (Otu *et al.*, 2016).

In September 2014 the Bill & Melinda Gates Foundation committed USD\$50 million to scale up emergency efforts to contain the Ebola outbreak in West Africa, with initial support of USD\$10 million given to UN agencies and towards the development of treatments and vaccines. This is an example of the cascade of financial flows that accompany certain epidemics and certain diseases and specifically target medico-technical interventions.

At the second OHCEA Conference in Kampala between 16th and 20th November 2015 a proposal from Makerere University, *College of Engineering, Design, Art & Technology* presented a design for an isolation centre based on ‘cultural considerations’ (OHCEA, 2015). The design intervention was funded under a USAID programme, *Resilient Africa Network* (RAN) supporting a 20 university partnership in sub-Saharan Africa towards the development of innovations for natural disasters. The proposal demonstrated a concept design and construction of a state of the art Ebola specific treatment isolation hospital at Mulago Referral Hospital in Uganda’s capital, Kampala. The rationale for such a development would be questionable at a National Referral Hospital currently serving a population of over 24,000,000 (Table 1.2) where hundreds of patients seek access to maternal and child health care, oncology and communicable disease services on a daily basis but limited resources and treatment actually exist to facilitate them. EVD outbreaks can occur anywhere and from the history of previous outbreaks in Uganda, a future outbreak is more likely to occur in an isolated rural community. Such an innovation assumes a large outbreak occurring in Kampala or involves the risk of transporting patients to the unit from elsewhere in Uganda. The time and resources invested in such donor led innovations needs to be reconsidered when compared to available, realistic, and cost effective interventions such as local isolation facilities, adequate fluid therapy, and monitoring of blood biochemistry during patient treatment. A focus on innovations during crises have been critiqued in the past as short-term emergency efforts referred to as ‘silver bullets’ that neglect to value more basic and evidenced based needs. The RAN -Makerere example reflects a knowledge gap between donors, academics, and local realities on the ground.

This section of the literature review provides a comprehensive understanding of EVD from a biomedical perspective. However a growing volume of knowledge in one discipline does not always translate into appropriate response interventions, particularly in terms of individual patient treatment or addressing underlying factors of EVD emergence and transmission in resource poor contexts. This may reflect a paucity of evidence-based research, particularly from those who have experienced EVD outbreaks and managed patients in context. In addition to a biomedical perspective, cultural understandings and social determinants of EVD emergence were also searched for within the literature.

2.5 Cultural and Social Determinants of Disease

Beyond what is known about EVD from a biomedical perspective, this section considers literature inclusive of the cultural and social determinants of disease relevant to EVD outbreaks.

2.5.1 An Inter-disciplinary Approach to Understanding Disease Emergence

Understanding disease from within the positive disciplines of epidemiology, virology or clinical medicine described above offers a very different perspective than from within the disciplines of social science or anthropology. The latter disciplines explore the role of social, cultural, and political determinants of disease as possible underlying factors to its emergence beyond the biomedical model offered by the former. Researchers have been criticised as viewing health challenges from within the limited framework of their specialised disciplines. The term ‘naïve expert’ was used to convey this limitation to knowledge sharing across the traditional boundaries of research at the *Bamako Call for Action on Research for Health* in 2009 (McLachlan, 2009). The rationale for sharing knowledge across disciplines is to contribute towards the generation of informed policies for organising more effective and sustainable response interventions towards epidemics.

The re-emergence of the ‘One Health’ concept has sensitised some health experts to acknowledge the potential importance of inter-disciplinary approaches towards understanding disease emergence and intervention (Hewlett & Amola, 2003). ‘One Health’ is a term introduced by the Wildlife Conservation Society in 2004, which captured it within a ‘One World-One Health™’ trademark. The society described the term ‘One Health’ as a concept supporting an idea that challenges facing the health of people, domestic animals, and wildlife and the integrity of ecosystems in the 21st century can be

met through a collaboration of expertise across various disciplines, sectors, and global regions through sharing innovative solutions. The history of interdisciplinary approaches to health and comparative medicine can be traced back through the centuries as far as the Zhou dynasty in China in the 11th and 13th century where integration of the disciplines of veterinary and human public health were recorded (Zinsstag *et al.*, 2011, Schwabe, 1968; Cassidy *et al.*, 2012). This ecological understanding of epidemic infections had also been explored in the period between the first and second World Wars when approaches in ecology, epidemiology and tropical medicine began to converge around the analytic categories of ‘environment’ and ‘disease’ (Tilley, 2011, p.184).

The inclusion of anthropology into global health has been more recently acknowledged as an important component of understanding disease and illness as it considers the narratives and framing of disease through a broader lens. Anthropologists offer plausible explanations for disease outbreaks within communities from a variety of perspectives. The role of cultural anthropology for example, has been considered in previous EVD outbreaks (Hewlett & Amola, 2003). EVD remains the only disease to date where the WHO has sought anthropological knowledge during an epidemic response (Hewlett & Hewlett, 2008). This inclusion of anthropology into the WHO biomedical response model has received opposing views in the literature. Leach (2010) views its integration in a positive light “as a key contribution to enlighten and re-value cultural models of disease and framings of system dynamics, and on identifying valuable health enhancing local knowledge and cultural categories which can be blended productively with scientific knowledge. The role played by anthropologists has also been criticised as selling out anthropology as ‘a handmaiden to epidemiology’ and subtly enforcing the assumption that behaviour is culturally determined ignoring the social, political, economic and historical factors that affect health outcomes and disease distribution (Jones, 2011). More recent anthropological literature however has seen a shift beyond the limitations of conveying a cultural understanding of EVD among local populations towards integration of these broader determinants. A sub-discipline of anthropology referred to as ‘critical anthropology’ has more recently entered the realm of global health. Reversing the focus from the local to a global perspective, Larkan *et al.*, (2015) refers to how the discipline of anthropology is uniquely positioned to consider the geopolitics of EVD outbreaks in global health.

Following the West African outbreak anthropologists expressed disappointment in their role in EVD policy (American Anthropology Association, 2014; Menzal & Schroven,

2017). Initially anthropologists perceived their role in EVD outbreaks to provide alternative perspectives informed by participatory and evidence based field research. They believed this could offer deeper and more nuanced understandings of the local situation in the affected communities that could inform more appropriate humanitarian efforts and improved policies that respond to peoples basic needs during EVD and similar epidemics (Menzal & Schroven, 2017). However the enthusiasm initially felt among anthropologists that the practical application of their expertise to policy relevance has since waned in the realisation that their role in EVD outbreaks is limited to service provision and public relations in the global North. This service provision lies within the confines of a cultural understanding of EVD outbreaks as an inherent element of sub-Saharan Africa that needs to be contained through improved community surveillance.

Despite justification for a shift towards an inter-disciplinary approach as a more effective means of informing global health policy in developing response interventions towards epidemics, lessons from the West African outbreak reveal that consideration of the wider issues of EVD emergence have yet to be fully embraced (Gostin & Friedman, 2014; Kruk *et al.*, 2015). The following sub-sections describe some of the understandings of EVD emergence available in the literature at the time of writing from a cultural and social perspective. In section, 2.6 available literatures on the broader geopolitical features of EVD outbreaks are also outlined.

2.5.2 Cultural Understandings of Ebola Virus Disease

Disease and illness can be interpreted as ‘a set of beliefs, assumptions and understandings about the nature and aetiology of a disease shared by members of a given population’ (Leach & Hewlett, 2010). Factors such as gender, religion, or cultural background influence how diseases are differently understood. Douglas (1992) considers how individuals and groups perceive social problems, including disease based on their social environments (the communities, institutions or nations) referred to as the *Cultural Theory* of disease.

In a study conducted between 2000 and 2001, a cultural theory of EVD emergence among the Acholi people in northern Uganda was identified (Hewlett & Amola, 2003).

Traditionally the Acholi understood EVD or similar epidemics as *two gemo* meaning a spirit force that descended suddenly and rapidly affected many people. *Two gemo* is

believed to descend on a community that has disrespected *Jok* (the spirits or gods). The community responds by implementing a traditional protocol that involves isolation and limiting the movements of those affected by the epidemic (Table 2.2).

Table 2.2: Acholi Traditional Protocol to Control Epidemics (Gemo)

These methods are utilised only when the illness has been identified and categorised as a killer epidemic (<i>gemo</i>).
1. Quarantine/isolate (<i>genko</i>) the patient in a house (<i>ot</i>) at least 100 meters away from all other houses. <i>Bobodu</i> should be allowed to visit the patient.
2. A survivor of the epidemic feeds and cares for the patient. If no survivors are around an elderly woman or man will be the caregiver.
3. Houses with ill patients should be identified with two long poles of elephant grass (<i>lum-lagada</i>), one on each side of the door.
4. Villages/households (<i>doggang</i>) with ill patients should place two long poles with a pole across them to notify those approaching the village/household.
5. Everyone should limit their movements, stay in their household (<i>doggang</i>) and not move between villages.
6. Do not eat any food from outsiders.
7. Pregnant women and children are especially prone to epidemics and should be especially careful to avoid the patient.
8. Increase harmony within the household, no harsh words or conflicts within the family.
9. Nobody should have sex.
10. Nobody should dance.
11. Do not eat rotten or smoked meat, only eat fresh cattle meat.
12. Once the patient gets better (no longer has symptoms) they should remain in isolation for

one full lunar (<i>dwe</i>) cycle before moving freely in the village.
13. If the person dies, the survivor/attendant buries the person and the person is buried at the edge of the village.

Source: Hewlett & Amola (2003)

In this study an analysis of the cultural understanding of EVD from the perspective of the community experiencing the epidemic offers new insights into ‘modern’ disease approaches. The Acholi study portrays how traditional protocols used during epidemics can be health promoting and reflect contemporary epidemiological models of preventing disease transmission. According to Weiss (2001), ‘cultural epidemiology’ refers to an interdisciplinary field of research between anthropology and epidemiology that explores locally understood meanings of illness and their distribution in cultural context.

This study highlights an example where cultural understandings of disease differ greatly yet response interventions converge at a common interface to control transmission of the disease at the community level. This example highlights how consideration to local understandings of disease, illness, and response interventions are an important component of implementing a control strategy within this community.

In a more recent example, the introduction of cremation as a government directive for burials of EVD victims in Liberia during the West African outbreak where mass burnings of over 100 bodies in incinerators donated by NGO’s occurred (Williams, 2015). This policy was particularly problematic to the community who were denied the dignity of a final farewell, confirmed cause of death or knowledge of the resting place of their deceased family member. This example conveys where a policy objective failed to consider the cultural or humane aspects of the community during an intervention.

2.5.3 Cultural Theory of Disease and Blame

Douglas (1992) describes how understanding disease emergence often comes in the form of blame. One such view is moralistic where the individual victim is blamed for becoming infected (Douglas, 1992). As conveyed in the Acholi example above some cultures may interpret sudden illness as a result that a community or individual has disobeyed the god(s), spirits or ancestors and therefore that individual or group are being cursed or punished. A

literal understanding of this belief from an external perspective may interpret it as backward or ignorant. The underlying meaning however may act as an empirical warning to the wider community that if one disobeys the laws of that society misfortune may ensue.

Jones (2011) comments on this perspective as a culturally determined epidemiology that has become exaggerated and exoticised in western consciousness through a globalised media.

Ebola has been exoticised, associated with traditional practices, local customs, and cultural beliefs, and insinuated to be a result of African ignorance and backwardness. (2011, N.p, Ghjournal.org)

Going on to argue that a hyper focus around EVD and culture is a “rhetorical racialization of the disease”, framing African culture as a “risk factor” that hinders modern control efforts (Jones, 2011). The prolonged West African outbreak (2013-2016) provided an opportunity to develop more informed understandings of EVD outbreaks. Despite this, however the West African outbreak displayed a cultural epidemiology within the popular and scientific literature. The following excerpt was taken from a paper written by “the WHO Ebola response team” consisting of over 60 authors.

“We infer that the present epidemic is exceptionally large, not principally because of the biological characteristics of the virus, but rather because of the attributes of the affected populations and because control efforts have been insufficient to halt the spread of infection” (Aylward *et al.*, 2014, p.1487).

Reference to the “attributes of the affected population” suggests a culturally determined epidemiology regarding the scope of transmission. The comment supports Byron Good’s (1994) argument that “while new explanatory models may be introduced, it is clear that changes in medical rationality seldom follow quickly”, (1994).

A second form of blame for the explanation of disease emergence explored by Douglas (1992) is to fault an adversary. The moral of framing a disease as an adversary is that everyone needs to be smart and protect one’s self-interest in order to survive. The adversary could be the threat of a bite from an infected reservoir host such as a mosquito in the case of malaria. It is therefore understood that to protect oneself a potential victim must ensure to employ precautionary measures such as using a mosquito net.

Throughout history, illness and disease have been presented in the form of an adversary using metaphors. Sontag (2001) specifically explores the punitive impact of cancer,

tuberculosis, and HIV as something other than a disease. She highlights how cancer was sometimes framed as “an evil invisible predator”, TB as a disease “of thin garments, thin bodies, unheated rooms, poor hygiene and inadequate food”. Metaphors are sometimes used to construct narratives and imagery in order to influence public opinion and support government policies. Sontag refers to the “language of political paranoia” evidenced through the use of metaphors such as “alien take-overs” and “invaders” was used to describe the pathophysiology of HIV in the 1980’s. She argues how such language was used to construct “an ideally comprehensive illness in the era of Star Wars and Space Invaders” (Sontag, 2001). Similarities exist between this type of imagery and the EVD narratives sometimes expressed in popular literature. Prior to the more recent West African outbreak, Ebola Virus Disease had received much publicity and media attention in westernized countries where its ‘enemy’ status can be attributed to imagery facilitated by fiction and media hype (Farmer, 1999a). Ebola Virus Disease gained considerable international attention through exaggerated accounts of blood oozing from body orifices and sensationalised newspaper headlines that humanized the virus as “a killer virus” or “a killing ghost, like Jack the Ripper” (BBC, 2014; CNN, 2014). The potent virulence of the virus into western consciousness was also portrayed through a number of Hollywood productions such as *Outbreak* (1995) based on Richard Preston’s novel, *The Hot Zone* (1994) and *Contagion* (2011) directed by Peter Soderbergh that portrayed EVD as an imminent pandemic threat.

The third understanding of disease and illness is to blame a higher force. The outside enemy may refer to larger causal factors or structural determinants of disease and represent views frequently held in the social, ecological and political sciences. Blame for the emergence of disease among a given population may be attributed to government policies on land use changes or a conflict situation that displaces populations and disrupts livelihoods. The socio- ecological model also argues that prevailing structural inequalities have led to increasingly unsustainable patterns of consumption and production and emerging infectious diseases are a symptom of this (Lee & Dodgson, 2000). This is sometimes referred to as political ecology. While the area of research into the social and environmental dimensions of human health has been investigated to a certain degree, the role of political ecology in increasing vulnerability to disease and shaping health decision-making is less common (Lee & Dodgson, 2000). According to King (2010) health is structured by the political and economic systems, which can create the conditions that influence the transmission of disease.

2.5.4 Racialization of EVD and Colonial Ideology

A persistent reference in western narratives towards African culture as a determinant of 'bad' behaviours associated with EVD emergence may reflect an expression of racialism embedded in colonial ideology. The term 'racial' refers to the concept that there are inherent differences between races beyond a racial hierarchy. 'Racialism' refers to beliefs of racial hierarchy and supremacy, most often applied to racial difference in intelligence. Franz Fanon (1968) put forward the theory that racialism is not just based on perceptions generated from physical differences between races but argues that a social basis underlies these mental evaluations (Fanon, 1968). Exploring this social basis of colonialism and racial ideology' he argued that colonialism and racial forms of expression dehumanise people and generate a self-understanding by the oppressed that they are outside the scope of humanity or inferior. The argument that 'cultural epidemiology' posits African societies as backward and ignorant and differentiates them within the realm of global health as 'other' derives from this social basis of colonialism.

It could also be argued that 'cultural epidemiology' is a neo-colonial ideology that remains embedded subconsciously or otherwise in the popular and scientific language surrounding EVD emergence in Africa (Jones, 2011). Bass (1998, p.446) describes this as a "hegemonic residue of imperial contamination [which] remains embedded in our culture".

In the West African study described above where reference to the 'attributes of the affected population' as a barrier to control efforts (Aylward *et al.*, 2014, p.1487), refers to the people of Guinea, Liberia, Nigeria, and Sierra Leone. This generalisation supports a racialised view relayed through narratives that often ignore the vast assemblage of African societies and civilisations and the massive cultural diversity that exist even within individual countries. It also posits Africans as a homogenous group whose thoughts and actions are governed by culture and beyond rational thought. Gilroy (1993) supports the argument that perceptions on culture among races are assumed to be a fixed entity of the groups they attempt to describe or define, 'a pseudo-biological property of communal life'.

2.5.5 Structural Violence

According to King (2010) health is structured by the political and economic systems, which can create the conditions that influence the transmission of disease. The moralistic

and adversary blame narratives outlined above offer no deconstruction of larger causal factors beyond the infection-host-environment framework. Absent from this model is a systematic analysis of the social processes that influence the vulnerability of groups and individuals to disease and exposure, a term coined as ‘structural violence’ (Galtung, 1969). Farmer (1999, 2005) highlights several case studies from across the world linking modern anthropology to the large-scale social and economic structures underlying disease emergence and adverse outcomes for the poor. One example includes the plight of the rural community in central Haiti displaced from their land to the overcrowded slums of Port-au-Prince following the construction of a hydroelectric dam. This upheaval determined by historical and economic forces was strongly correlated with the emergence of HIV among the rural Haitian population (Farmer, 1999). This is an empirical example of ‘structural violence’.

Less emphasis is placed on the socio economic determinants of EVD emergence, despite a medium volume of literature from critical anthropology having entered the field of global health in recent years. While some efforts have been made to adopt an inter-disciplinary approach to research for health by considering the cultural and social dimensions of EVD emergence, the research remains lacking. The next section considers the role of geopolitics, particularly the power dynamics between the global north and south in shaping global health decision-making and outcomes (Lee & Dodgson, 2000).

2.6 Geopolitics of Ebola Virus Disease

This section begins by providing a background to the development of international health and the relevance of emerging infectious diseases on the international stage. This helps to position Uganda and its experience of EVD outbreaks within the realm of global health and more specifically within the geopolitical framework of global health security.

2.6.1 History of International Health

Historically the term ‘international health’ relates to the links between trade and health traced back to the Black Death, which followed international trading routes in the 14th century (Taylor, 1996; Chen *et al.*, 1999). In the 1830’s cholera, an endemic disease of South East Asia spread through Russia and the Middle East to Europe and eventually

America via shipping trade routes killing tens of thousands and inciting their governments to impose stringent quarantine and isolation methods (Evans, 1988). By 1851, international diplomacy and science merged to initiate the first International Sanitary Conference on standardising quarantine regulations for cholera in France (Howard-Jones, 1975). Cholera as a threat to international trade remained the dominant subject of discussion at thirteen subsequent International Sanitary Conferences (composed of European and American delegates) that followed between 1851 and 1938 (Howard-Jones, 1975). These events led to negotiating health measures that prioritised those diseases perceived to be the greatest risk to travel and trade, with an emphasis on diseases emerging from Asia and the Middle East, the main trade routes to Europe and America at that time. These control regimes were to be implemented by imposing quarantine measures at ports of exit and entry, developing reporting mechanisms of ‘mutually high priority diseases’ to other member countries that might be affected and by maintaining adequate public health capacities to protect themselves from imported outbreaks. These co-operations led to the foundation of a number of international public unions including the *Pan-American Sanitary Bureau*, the office *d’International Hygiene Publique* and the *Health Organisation of the League of Nations*. In 1948, this led to the creation of the World Health Organisation (WHO) as a specialised agency under the United Nations (UN), which incorporated these preceding organisations (Siddiqi, 1995). In 1951, the WHO consolidated the various preceding conventions and regulations into the *International Sanitary Regulations* mandating member states under international law to monitor, report and control six specific infectious diseases. These diseases included small pox, relapsing fever, typhus, cholera, plague, and yellow fever (Siddiqi, 1995). The 1951 regulations were updated and renamed the *International Health Regulations* (IHR) in 1969. The main objective of the IHR was to prevent the spread of certain diseases while protecting trade and travel to remain unchanged.

With the scientific discovery and contribution of the ‘germ theory’ and the subsequent advancement in the developments of vaccines, antibiotics and vector control, the perceived threat of importing ‘exotic’ diseases into the industrialised nations of the global north waned. In 1979, with the eradication of small pox and the advances of public health and modern medicine benefitted by these same industrialised nations, the original list of internationally notifiable infectious diseases had contracted to three namely yellow fever, cholera, and plague.

2.6.2 Global Health Governance

According to Fischer *et al.* (2011) the traditional distinctions between national and international public health changed under processes of globalisation. The term ‘globalisation’ refers to the process of interconnectedness between societies such that events in one part of the world increasingly have influence on people and societies far away (Fidler, 2001). Originally, the term *globalisation* has been more commonly used in relation to trade, communications, and financial markets but has more recently transcended into the health domain. The globalisation of health is not an enigma considering that the history of international health accompanied the history of trade. In the 21st century, the concept of international health has moved beyond controlling diseases at national borders and progressed towards an exploration of broader health issues including health outcomes, policies and systems within and between nations. This broader concept of international health has more recently been referred to as ‘global health’.

Aginam (2005) reasons that global health governance derives from the concept of global governance that became popularized in the 1990’s influenced by the Commission of Global Governance (1995) as an emerging concept within international relations. Governance of international health issues at the start of the 20th century was based on international diplomacy informed by the development of science. Contemporary global health governance has shifted away from the WHO as a central governing body towards an array of state and non-state actors and agencies. These multi-party stakeholders derive from the private sector, international, non-governmental and philanthropic organisations and attempt to collaborate, influence and claim authority over development policies for health (Horton, 2015). Dry (2010, p.23) refers to these collaborations collectively as the ‘organizational landscape of global health’.

What appears analogous between the historical organisation and objectives of international health and the contemporary phenomenon of global health is that they remain dominated by northern actors and institutions predominantly serving northern interests. The 21st century phenomenon of ‘emerging infectious disease’ within the realm of global health is one such example.

2.6.3 Emerging Infectious Diseases

Since the beginning of the 21st century, the world has become conscious to a number of global challenges including exponential population growth, competition for limited resources, inequalities, macro-economic instability, terrorism, and climate change. These challenges are interlinked and underlined by common determinants. For example industrialisation and an over reliance on fossil fuels has resulted in mass deforestation and temperature increases underlying extreme weather events such as floods and droughts affecting agriculture, food prices, infrastructure, human and animal migration and human health. As outlined above (section 2.3.3), neoliberal policies and globalisation between the predominantly agrarian economies of sub-Saharan Africa and international economic flows result in growing inequalities between the rich and poor nations aggravated by the effect of climate change (Thomas & Twyman, 2005; Harrison & McMillan, 2007). Resultant poverty including mass unemployment among the youth is a major challenge of the 21st century.

In addition to globalisation world travel and trade has increased, and the emergence of new diseases serve as a reminder to the industrial economies that the battle against unpredictable pathogens is not a thing of the past despite the optimistic medical advances of the previous century. These new diseases referred to as ‘emerging infectious diseases’ are defined as an infection that has ‘newly appeared in a population or had previously existed but is rapidly increasing in incidence or geographic range’ (Morse, 1996). The phenomenon came about in part or in combination with more frequent or recognised occurrences and advanced diagnostic technologies. It is also argued that contemporary global health challenges exceed those of earlier periods by an order of magnitude because of the speed and density of population movement across borders increasing the risk of disease transmission between and within countries (Bogich *et al.*, 2012; Burgos & Otte, 2008; CDC, 1998). The term ‘disease knows no borders’ is frequently used to demonstrate this concept.

In 1981 human immunodeficiency virus, (HIV) first surfaced in North America and was traced back to a disease that had existed in endemic proportions in urbanised areas of West Africa for decades (Poulsen *et al.*, 2000; Lerney *et al.*, 2003; Esbjornsson *et al.*, 2011). The concept of ‘emerging infectious diseases’ followed the emergence of a number of novel pathogens that followed the HIV/AIDS pandemic. These included Severe Acute Respiratory Syndrome (SARS) that emerged from China in 2002 and was recognised as

the first severe infectious disease of the 21st century to pose a serious threat to ‘global’ health security and to the stability and growth of economies. This was followed later by another novel disease threat, the H1N1 swine flu pandemic emerging from Mexico during the period 2009 and 2010 (Charu *et al.*, 2011). H5N1 highly pathogenic avian influenza (HPAI) also arrived among these novel viruses and continued to spread through ecologic and economic transformations posing a potential threat of mutating to a human-human transmission (Cubley *et al.*, 2008). Ebola and Marburg, referred to initially as the haemorrhagic viruses were more frequently reported from within sub-Saharan Africa (WHO, 2012b). In addition to these ‘new’ viruses, old diseases such as tuberculosis and malaria were also displaying resistance to modern medicine and were added to the list of ‘emerging and re-emerging infectious diseases’ (Farmer, 1999b; Morse, 1996; Leach & Dry, 2010).

Some authors argue that the concept of ‘emerging infectious diseases’ is used as a justification to shift global health priority towards diseases perceived by wealthier nations as a potential threat to them.

“If certain populations have long been afflicted by these disorders, why are the diseases considered ‘new’ or ‘emerging’? Is it simply because they have come to affect more visible-read, more ‘valuable’-persons? This would seem to be an obvious question from the perspective of the African poor” (Farmer, 1999, p. 39).

Despite the global burden of infectious diseases such as malaria, cholera, and typhoid (long entered into the history books of Europe and north America) borne by fragile health systems in sub-Saharan Africa, priorities in global health have become skewed towards these ‘emerging infectious diseases’. This also became evident by recent policy changes to the International Health Regulations in 2005.

2.6.4 Revision of the International Health Regulations (IHR)

In 2002, the SARS virus spread to 25 countries resulting in over 800 deaths. Economic losses were estimated at between US\$30 -50 million (WHO, 2003b). China however was under no legal obligation to report the disease under the IHR regulations at that time and the WHO had no legal authority to demand information. In response to this oversight and with an increased incidence of ‘emerging infectious diseases’ the WHO revisited the IHR. In 2005, the 1969 IHR’s were revised and adopted by the 58th World Health Assembly

(WHA) for implementation by June 2007 (WHA, 2013). The revised regulations legally bind all 194-member states to the timely reporting of all incidents that pose a ‘public health emergency of international concern’ (PHEIC) occurring within 24 hours of detection. Declaring an event as a PHEIC is based on three main criteria: an event that has the potential to spread ‘internationally’, an event that is considered ‘unusual or unexpected’, and an event that has ‘significant potential to restrict travel or trade’. EVD among other ‘emerging infectious diseases’ are classified as potential PHEIC’s and have gained considerable international attention within the realm of global health security and western public consciousness in recent decades.

All member countries are legally obliged to ensure that they strengthen their public health surveillance and response systems as a core priority underlying their public health systems. They are mandated to have adequate capacity for surveillance, reporting, notification, verification, response, and collaboration activities in place. The revised regulations also mandate member countries to develop legal and regulatory mechanisms to ensure that all IHR obligations are met from national to local level (Calain, 2006). The main aim of the revised IHR is based on creating an integrated international surveillance network to contain threats to ‘global’ health security when and where they occur (Calain, 2007a). A five-year deadline from the date of implementation (2007 - 2012) was put in place for all countries to meet IHR compliance.

However, the revised IHR provided no formal source of funding to low or middle-income countries to make the required investments for development (Fischer *et al*, 2011). Donor countries are encouraged to support health system strengthening in the areas of surveillance and response capacities in developing countries justified as an investment in their own national interests (Fisher *et al*, 2011). Partnering it is claimed ensures that if other countries possess the capacity to detect and respond to a public health event before it spills across borders, this would protect their vital interests at home and abroad (Fisher *et al*, 2011).

In the aftermath of the 2014 - 2016 Ebola epidemic in West Africa, delays in the decision making process to declare it a PHEIC were critiqued (Gostin & Freidman, 2015; Heymann *et al*, 2015). WHO declared the epidemic a PHEIC in August 2014, four and a half months after the outbreak had transcended international borders. This puts into question how the institutions governing response to pandemics define ‘international’ in relation to the African continent despite all three criteria for a PHEIC being met. By the time the outbreak

was declared a PHEIC it had spread across four West African countries; Guinea, Liberia, Sierra Leone and Nigeria with over 3,000 probable, confirmed and suspect cases and over 1,500 deaths reported among West Africans (WHO, 2014a).

An observation was made that the delayed declaration of a PHEIC in West Africa followed the death of two US citizens (Gostin & Friedman, 2015). In addition, a stark contrast was observed between the delayed interventions to the EVD outbreak in West Africa compared to the subsequent declaration of Zika virus as a PHEIC in 2016. Zika virus is a non-lethal pathogen identified in Uganda in 1947. Human reported cases were confined to equatorial Africa and Asia between 1952 and 2007. Spreading to French Polynesia in 2007 and 2014, it then emerged in a number of countries in South America including Brazil, Columbia, Guatemala, and Mexico in 2015. On February 2nd two cases were identified in Texas, USA and on the 7th February 2016 Zika virus was declared a PHEIC (Kindhauser *et al.*, 2016). A bias in priority towards certain infectious diseases threatening the social and economic boundaries of wealthier nations lies in paradox to the ‘disease knows no borders’ rhetoric. The stark inequalities between those who control the global health policy agenda and those who experience the contextual realities on the ground are evident. Why certain diseases are perceived and responded to, as global crises worthy of international intervention while others are not can be considered through the social theories of global altruism and political realism.

2.6.5 Global Altruism

The theoretical assumption of *global altruism* is based on the understanding that certain diseases including EVD are perceived to be a major threat to human health and security because they transcend international borders beyond their point of emergence. Global altruism posits that a collaborated global surveillance and response network is ‘a global quality’ or a ‘global public good’ (GPG). In other words, there is a justified moral political claim to respond to EVD outbreaks for the global good of all.

As outlined above in section 2.6.2 control of infectious diseases that had the potential to transcend international borders and threaten public health or cause restrictions to international travel or trade were traditionally under the sole mandate of the WHO. Section 2.6.3 makes reference to the emergence of an array of government and non-government institutions including private sector actors appearing across the global health landscape that

have influenced the policy agenda. One perspective posits that this diversity of international involvement supports the concept that global health has become an important objective of foreign policy and 21st century humanity (Bogich, 2012). Collaboration between donor and developing countries can support fragile health systems within impoverished communities where outbreaks such as EVD more commonly take place. This support in terms of financial, human, and infrastructural resources towards improved surveillance and response capacity may not otherwise be available to containing outbreaks.

The concept of global altruism has also been criticised as it predominantly targets specific diseases more likely to cross socio-economic rather than geographical borders (Chen *et al.*, 1999; Farmer, 1999). In stark contrast to the attention given to ‘emerging infectious diseases’, the burden of endemic disease experienced by the poorest countries including cholera, measles, typhoid and sickle cell disease are not promoted as ‘global public goods’ and remain outside the narratives informing most global policy agendas and intervention programmes.

2.6.6 Political Realism and Securitisation in Global Health

A second theory why certain health events are considered to be ‘global crises’ worthy of international intervention while others are not is the concept of political realism. Political realism considers the rationale that the ‘global’ community (dominated by the policy makers of Europe and North America) act out of self-interest because novel viruses including EVD are perceived as diseases that could be of major consequence to them.

In the USA, the Clinton Administration focused on HIV as a potential threat to national security and the destabilising affect it posed to severely affected countries. The HIV/AIDS pandemic was also perceived in the USA as a threat to undoing years of work invested in building free market democracies in Africa (National Intelligence Council, 1987).

Broadening the perception of HIV/AIDS as a security threat went a long way towards leveraging resources and political will to tackle the crises on a global scale and the disease dominated the landscape of international health for over two decades. The term ‘global health security’ originated as a concept from fears of bioterrorism that has since evolved to incorporate the idea of a ‘war on terror’ (Collier *et al.*, 2004).

According to the United States Department of Health and Human Services Ebola is classified as a Category A select agent (CDC, 2012a). According to Kalra *et al.* (2014),

EVD is now the infectious agent viewed as one of the greatest threats to global security warranting international collaborative efforts. Heymann *et al.* (2015) summarised the West African ‘calamity’ as a lesson towards “renewed attention towards global health security”. More recently, the term ‘emerging infectious diseases’ has been replaced with ‘emerging pandemic threats’ and a shift towards the securitisation and militarisation of public health in both theory and practice has occurred. In West Africa after an extended period of delay, response to the EVD outbreak came in the form of militarised intervention as the United Nations Security Council overshadowed the WHO involvement, when the UN Mission for Ebola Emergency Response (UNMEER) was launched to lead the response. This involved the deployment of over 10,000 foreign troops justified by the UN Security Council as mitigating the potential risk to ‘international security and peace’ (Gostin & Friedman, 2015).

Larkan *et al.* (2015) considers how this demonstrated a dramatic shift in global health securitisation, which should not go unnoticed or unchallenged. This shift in power from WHO to UNMEER during the West African outbreak (without an official mandate for the application of ‘diplomatic standards’ for military involvement in global health efforts) set a precedent that armed forces have the ‘best’ capacity for controlling future epidemics. This questions the limitations of state sovereignty in controlling future public health events of ‘international concern’ (Larkan *et al.*, 2015). Fidler (2007) points to how the new globalisation of public health, sometimes in the guise of ‘global health security’ has, to a certain extent orchestrated global health policy and has been criticised as undermining a sovereign state’s ability to prevent and control infectious disease (Fidler, 2005; Fidler, 2007). While collaborations in terms of logistics and the productive engagement of personnel and equipment normally deployed for destructive forces has certain advantages this also highlights a significant change in the power dynamics between the institutions governing global health and the diminished role of the WHO in response policy (Larkan *et al.*, 2015). The extension of securitisation beyond the boundaries of international politics into the realm of global health has been considered as verging on “inappropriate state involvement” (Ingram, 2005, p.524). Militarisation during Ebola outbreaks is not only limited to international response however. Okware (2002) refers to “security agencies” that were involved in the coordination of the Uganda outbreak in Gulu in 2001. Also, during the West African Ebola epidemic, the Liberian government deployed the military to establish a *cordon sanitaire* at West Point that resulted in violent clashes between government forces and the local community (Gostin & Friedman, 2015).

Adopting a securitised approach towards ‘global crises’ in countries where fragile health systems exist may be perceived as advantageous within the international political system, an attractive strategy for containment in terms of logistics and economic feasibility. Justification for this rationale maintains that health systems in these countries are fragile and do not have the infrastructural or human capacity to respond to major public health events. The military in these countries on the other hand have large numbers of highly trained personnel, sophisticated logistics and are funded by a significantly larger proportion of government budgets compared to health. Justification for adopting a securitised agenda towards EVD and similar epidemics requires international diplomacy between the responding and recipient nations. In other words, the ‘local’ decision makers must perceive interventions towards ‘global crises’ from the ideological perspective of global altruism rather than from the perspective of political realism. This can be facilitated through generating a ‘universal consensus’ supported through foreign aid programmes, diplomatic relations, or structures as a soft tool approach. Some argue that foreign aid undermines a state’s control and responsibility over its health needs and invites interference into non-health issues (Calain, 2007; Feldbaum *et al.*, 2010). The use of health interventions by state and non-state actors for foreign policy objectives is a controversial but growing part of health diplomacy (Feldbaum & Michaud, 2010; Manrique, 2012; Horton, 2007).

A militarized approach to controlling EVD or other epidemic outbreaks represents a realist perspective or a quick fix solution that appeases western priorities but fails to address the underlying structural determinants of EVD emergence. The key to preparedness cannot be to bypass health system strengthening with ‘emergency response’ approaches determined by foreign policy agendas. Sustainable preparedness needs to be considered as a combination of long-term goals towards universal robust health systems that consider national needs as a priority supported by a strong global health governing structure (Gostin & Friedman, 2015; Larkan *et al.*, 2015).

2.6.7 Universal Consensus & ‘One Health’ Concept

‘Universal consensus’ is a term used to describe an opinion or position reached by a group as a whole. Bennett & Edelman (1985, p162) argue that when stereotypical theories are repeated by an array of ‘reputable’ global actors they converge into a dominant narrative that becomes a rational ‘truth’. Dry (2010) refers to a universal consensus generated

around certain infectious diseases as the perceived generation of an inclusive, mobilised and concerted policy community working together to fight a common threat (Leach & Dry, 2010). Generating a social theory of ‘universal consensus’ has been critiqued however as having limitations as it may represent “*the views of the most privileged 600 million assuming the same views are experienced by the whole 6000 million who are actually in the world*” (Connell, 2007, p.212). This ‘truth’ is sometimes used to justify global policy based on the assumption that it is a ‘universal’ truth and therefore a global public good, although the voice of those whose reality is very different has never been included in the process. This concept is also referred to as *Cultural Hegemony*, a term used to describe those who adhere to the worldview or ‘norms’ of a culturally diverse society dominated by a ruling class. The theory claims that the ideas of the ruling class come to be seen as universal ideologies, perceived to benefit everyone whilst only really benefiting the ruling class.

As outlined above the origins of the One Health concept were founded on the idea that a collaboration of expertise across various disciplines, sectors, and global regions through sharing innovative solutions can address health challenges in the 21st century across the human- animal- ecosystem interface. The One Health concept has since gained considerable popularity and momentum among various stakeholders at the global level evidenced by the support from the major actors and institutions of global health, such as the WHO, the Food and Agriculture Organisation (FAO) and the World Animal Health Organisation (OIE) and bilateral donor agencies (FAO *et al.*, 2008a; Vallet, 2013). In addition, a number of International Conferences have taken place over the past decade supporting the ‘one health’ concept. As outlined above the concept reinvented by the WCS aimed at focusing attention on the protection of ecosystems to ensure the future health of wildlife, domestic animals, and humans. The concept however has more recently been embraced by powerful actors and used to generate a universal consensus specifically in relation to the securitised agenda.

In 2011 a High Level Technical Meeting was held in Mexico hosting a tripartite of the WHO, the FAO and the OIE who collaborated on an agreement that the One Health concept was used to promote the concept of cross border benefits and ‘a health for all’ agenda as a ‘global public good’ (FAO, OIE and WHO, 2011). A main resolution emerging from the Mexico tripartite agreement was to build political will and more actively engage Ministries in this ideological perspective through the One Health ideology (CDC, 2011).

In 2010, USAID launched a ten-year *Emerging Pandemic Threats Programme* I (2010-2015) and II (2016-2020) comprising four parallel projects, PREDICT, RESPOND, IDENTIFY, and PREPARE. The programme focused on sub-Saharan Africa and South East Asia framed as global “hot zones” for ‘emerging infectious diseases’ (Calain, 2007a; Bass, 2009). The programme was specifically directed at decision makers and academics in public health institutions. For example, the RESPOND project supported the One Health East and Central Africa (OHCEA) network, a collaboration of 14 academic institutions from veterinary medicine and public health and the ministries of health and agriculture. Initially the programme was implemented across six east and central African countries including Uganda, Rwanda, DRC, Tanzania, Kenya, and Ethiopia with two USA universities as implementing partners. In 2015, new member states joined from Cameroon and Sierra Leone. An overall goal of the programme was to build capacity among the next generation of policy makers to detect and respond to potential pandemic outbreaks in sub-Saharan Africa and South East-Asia. In the early stages of the programme the ideological perspective of global altruism was promoted through an international conference in Addis Ababa themed under “*One Health and the Control of infectious Diseases: Building Capacity, Systems and Engaging Communities*”. However a securitised agenda emerged two years later at the second 2nd OHCEA Conference hosted in Kampala, Uganda where a theme for *Strategic Approach to Global Health Security through One-Health Innovations: Vision 2035* was advocated. New funding supporters for the programme emerged at this second conference including the *United States Defense Threat Reduction Agency Cooperative Biological Engagement Program* and *Sandia National Laboratories*, a bioweapons agency. Essentially the concept promotes an ideological perspective and provides a useful tool to generate a ‘universal consensus’ thus facilitating access to the policy communities within the region.

Adopting the One Health concept as an ideology can facilitate universal consensus. It can also be argued that the ‘one health’ ideology is being used to push a dominant narrative surrounding ‘emerging pandemic threats’ overlying a securitised agenda. The Euro-American perspective of ‘emerging infectious disease’ as global health threats is translated to the teaching curriculums of medical, veterinary and public health schools globally contributing to a ‘one size fits all’ approach and promoting ‘corrective’ responses to disease emergence. Targeting activities at academic and ministerial elites seems is a long way from the front line health workers who manage epidemics within the impoverished health systems where they are most likely to emerge. From their perspective, activities

towards advocacy and promotion of the “One Health” concept might be viewed as a disproportionate allocation of international resources based on a global health agenda that does not provide justified evidence over local priority.

2.7 Local Experiences of Ebola Virus Disease

The previous section follows the development of international health from its origins aimed at protecting industrialised nations from importing epidemics from their traditional travel and trade routes. It questions the contemporary version of global health in terms of the power dynamics between northern dominated actors and institutions prioritising northern interests through political diplomacy. This section reviews the available literature on experiences of EVD outbreaks as events of global significance experienced from local perspectives. The concepts of ‘global’ and ‘local’ are first considered.

2.7.1 Global versus Local

According to Leach and Dry (2010) the term ‘global’ used in global health tends to be associated with powerful international institutions, modern scientific knowledge, technological advancements and expertise in risk analysis and top down surveillance by those who can mobilise quickly and offer protection and security to populations at risk of public health catastrophe. The term also refers to the institutions, actors, and narratives located in the global north that dominate international health.

“In these accounts the global is presented as powerful, scientific and ‘modern’ (for which read: Western)” (Leach & Dry, 2012,p.246)

On the other hand, the term ‘local’ tends to be associated with communities that are traditional, backward and remain outside the global system or the realm of modern science. The term ‘local’ has been portrayed above in section 2.5.3 in terms of culture and the ‘behaviour blame narrative’, where traditional practices or beliefs among local communities are blamed for risk of disease emergence, and an obstruction to control

measures. This dichotomy between the ‘global’ and ‘local’ is conveyed in much of the scientific and popular literature through a ‘them and us’ narrative. In western media, EVD has been frequently portrayed as something that can come from ‘there’ and affect us over ‘here’.

“there is a clear understanding that the outbreaks in West Africa are a threat to our health security – people with infection have travelled across borders within Africa to Europe and North America” (Heymann *et al.*, 2015 p.1884).

Research that captures ‘local’ experiences of EVD epidemics is scarce in the scientific literature and indigenous voices remain marginalised towards informing policy responses.

2.7.2 Fear, Stigma, and Resilience

De Roo *et al.* (1998) outline how fear and panic resulted in abandonment by patients and health care workers from Maridi General Hospital at the centre of the EVD outbreak in Kikwit, DRC in 1995. This occurred in response to infection among 61 out of 154 nursing staff including the death of 33 health care workers and eight ancillary staff at the hospital. In a retrospective study later conducted among patients including health care workers who survived infection during the Kikwit outbreak experiences of fear, denial and shame were reported. During their time in the isolation ward they witnessed fellow patients dying as health care workers absconded fearing to treat them. Neglect of Ebola infected patients by health care workers who fear to provide nursing care because they perceived death as inevitable in the absence of an Ebola ‘cure’ was also identified almost twenty years later during the West African outbreak, referred to as ‘therapeutic nihilism’ (Lamontague *et al.*, 2014, p.1565). In Liberia, children orphaned by EVD during the West African epidemic were reported as left to die in quarantine as a result of fear by care givers to intervene.

Many of these children do not survive quarantine periods, they just cry to death because no one can provide care from the outset (Abramowitz, 2015, N.p)

Patients who recover from EVD frequently report experiences of social isolation and stigma. In the Kikwit study survivors experienced physical rejection in the form of stones been thrown at them by their community and eviction from their households by family members who feared infection (De Roo *et al.*, 1998). In another study focusing on local experiences during the EVD outbreak witnessed in northern Uganda in 2000, fear

contributed towards exaggerated displays of precaution among the immediate community, including bathing in 'Jik' (a bleach reported as an effective disinfectant against the virus). In another report funeral mourners stripped themselves naked at the burial of a deceased person to prevent carrying virus on their clothes (Kinsman, 2012). Stemming from this culture of fear, a large number of survivors from this outbreak experienced extreme stigma on returning to their villages where they found their property and possessions burned and in many cases, they were rejected by family members and spouses. Those engaged in business experienced loss to their livelihoods as they were shunned at the market place. Health care workers and burial teams also experienced stigma within their communities (Kinsman, 2012). In this study, the contrasting behaviour of altruism was also identified among health care workers who displayed exceptional commitment to their patients. A consequence of this however was exhaustion and increased vulnerability to infection. Nineteen health workers died at St. Mary's Hospital in Gulu, northern Uganda including the highly respected Dr. Matthew Lukwiya, Medical Superintendent who succumbed to infection in December 2000 (Okware, 2002).

Similar experiences to those described above including fear, stigma and the exceptional commitment to patient care were also identified among other anthropological studies undertaken in the Republic of Congo in 2003 (Hewlett & Hewlett, 2005). A phenomenological study also undertaken in Kibaale, western Uganda in 2012 shares similar experiences among EVD victims with these previous studies (Matua, 2014). Feelings fluctuating between hope and despair during the period spent in the isolation ward. Following recovery survivors experienced a persistence of traumatic episodes manifested as fear, panic, and sadness. Fear generated behaviour among the community was also displayed in terms of stigma, rejection and social isolation for survivors from neighbours and family members. Similar to findings from the Gulu study outlined above survivors of the Kibaale study also reported on difficulties reintegrating into their communities and associated economic impacts.

Previous studies on EVD experiences also identified resilience among the affected communities and a transcendence of victimhood through behaviours of self-preservation. Other resilient behaviours included abandonment of posts and actively isolating those associated with infected persons or a survivor of the outbreak as a means of protecting the community (Kinsman, 2012; Matua, 2014). The role of actively protecting the community manifested as different semblances, sometimes as caregiver or healer and other times as vigilantes (Kinsman, 2012; Matua, 2014). Coping mechanisms identified among victims of

EVD included seeking spiritual protection through prayer and religiosity (Hewlett & Hewlett, 2005; Kinsman, 2012; Matua 2014), adopting positive attitudes or to relinquish and accept their fate (Matua, 2014). Other adaptive behaviour included avoidance, distancing and withdrawal (DeRoo, 1998; Hewlett & Hewlett, 2005; Kinsman, 2012; Matua, 2014).

2.8 Chapter Summary

2.8.1 Key Findings from the Literature

The literature review for the thesis was formulated by extracting information from multiple themes found within the main research objective. These included a background to the context of western Uganda, understanding EVD emergence, amplification and response from a biological and clinical perspective as well from social, cultural and geopolitical perspectives. The key findings of the review are summarised in this concluding section around the concept of power, identified as the common thread running through each of the sections outlined above.

The first section outlines the historical and political context of Uganda from where the EVD outbreaks in this study emerged. This gave a brief snapshot of the historical sequence of authoritarian political order tolerated by Ugandans since the eighteenth century from the emergence of kingdoms, colonialism, post-independence dictatorships and a violent civil war. Although Uganda has enjoyed relative peace and economic stability for the past thirty years emerging as a single party ‘democracy’ it remains overshadowed by a global capitalist system and external neoliberal policies that have resulted in growing inequalities since the ending of the cold war. The mass influx of refugees from eastern DRC into western Uganda is a consequence of war modes of production and expansive interests linked to Ugandan and Rwandan extractive and security interests. This post-Cold war political economy that guarantees access to cheap resources for global corporations whilst costing the lives of over three million Congolese people lies subordinated to a cultural epidemiology that defines and blames those same Congolese as refugees for their eating habits and subjecting the region to EVD outbreaks.

EVD is well documented from a biological perspective, however a comprehensive understanding of its biological form, clinical manifestations, and pathophysiology in

humans does not necessarily translate into cost-effective and common sense treatment being made available for the majority of Africans during outbreaks. Perceived as a threat to western public health and security, donor led interventions and financial support flows inwards in the form of responses that focus on containment and research for vaccine and innovative drug developments. The geopolitics of current response interventions are outlined against the history of ‘international’ health emerging from the development of northern institutions serving northern interests. An overview of contemporary global health diplomacy and the construction of ‘universal consensus’ among decision makers to support an increasingly securitised agenda is considered in view of the inequalities of health interventions and outcomes during EVD outbreaks. The third section broadens the lens beyond the biomedical framework by capturing some of the cultural and social perspectives around EVD outbreaks. The concept of ‘cultural epidemiology’ was supported for its consideration of anthropological perspectives. However, the role of anthropology in EVD epidemics has been confined within the limitations of offering a culturally determined explanation for EVD emergence and amplification but excluded from offering a critique of the larger structural forces underlying it. The determinants of war and conflicts that are commonly associated with EVD emergence and the role of unresolved poverty and weak health systems have remained subordinated to a behaviour blame narrative. Finally, local experiences from a limited number of studies are mostly descriptive and converge around human understandings through a psychological perspective of human experience. Figure 2.1 summarises the multidisciplinary perspectives applied to current understandings of EVD identified from the literature.



Fig. 2.1 Interdisciplinary perspectives and concepts around Ebola Virus Disease

2.8.2 Gaps in the Literature

While collaborative work between international, national, and local teams to contain outbreaks of highly virulent pathogens at source remains important in developing countries, an imbalance exists in the knowledge disseminated in the scientific literature and the narratives around EVD outbreaks that are dominated by inputs from the global north. The voices of those directly involved are seldom included.

This review of the literature reveals how EVD outbreaks have been well documented in terms of biological and epidemiological perspectives. Several studies make references to plausible underlying determinants but none actually explore these causalities analytically. For example, one abstract makes reference to how “*Specific conditions in hospitals and communities in Africa facilitate the spread of the disease*” (Baize, 2014, p.1418), but no further reference to the ‘specific conditions’ are mentioned in the main article. In another study in Guinea the author suggests that continued transmission of the virus was due to “localized resistance to EVD interventions, in addition to limited awareness and acceptance, fear, mistrust and stigma”. However the author then goes on to claim that a reason for high transmission was due to high mobility in and out of the capital city by “patients seeking medical services not available elsewhere” (Rico *et al.*, 2016. p.). Here limited access to health services contradicts the behaviour blame narrative but is overlooked. The article makes no references to poverty, lack of health system infrastructure or the fact that the West African countries affected are amongst the lowest on the human development index (UNDP, 2014). The literature around natural infection among wildlife make some references to the challenges that unbalance the ecosystem such as logging and deforestation but again a deeper exploration of these determinants remain absent (Formenty *et al.*, 1999; Wolfe *et al.*, 2005). According to Leach & Hewlett (2010) models looking at infectious disease emergence need to be dynamic, systemic, and critical. They need to track rapidly changing clinical, even molecular phenomena and then link them to the large-scale social forces that shape the contours of disease emergence. This broader exploration of the underlying determinants of EVD outbreaks has been mostly neglected to date (Dry & Leach, 2010).

What emerges from the review as a major gap is the lack of local voices in terms of interpretations and lived experiences throughout the events and their contribution to knowledge. While a few studies on previous EVD outbreaks in Uganda have explored local perspectives and lived experiences during EVD outbreaks, none have linked them to

the broader determinants that underlie their emergence or outcomes (Hewlett & Amola, 2003; Kinsman, 2012; Matua, 2014). In 2015, the *Lancet* invited a number of “respected global health practitioners to reflect on lessons learned from the West Africa outbreak, to explore the idea of global health security, and to offer suggestions for next steps” (Heymann *et al.*, 2015, p.). None of the authors hailed from the West African countries where the epidemic occurred, or from a country where Ebola had ever occurred in the past. Only one member originated from an African institution in South Africa, the New Partnership for African Development (NEPAD), an institution that has been critiqued as a privileged strata of African elites that fit into existing global power relations (Taylor, 2003).

Inclusion of the perspectives of local health service providers working directly with infected persons and at risk of infection themselves could offer deeper insight into the role of how international responses were perceived and the long-term impacts, if any on the health system during and following the outbreak. An understanding of these perspectives could identify gaps and valuable lessons learned.

The challenge of managing and controlling EVD outbreaks from within impoverished communities in sub-Saharan Africa where they are most likely to occur provides a rich context for arguments from the biomedical, cultural and socio-political models of disease emergence in addition to the epidemiological and behaviour based narratives in situ. Secondly, there is clearly a space in the literature for a deeper analysis to understanding the broader dynamics shaping the emergence of EVD outbreaks from local as well as national and global perspectives. This knowledge can be transferred to global and national policy makers in developing improved and sustainable response mechanisms into the future.

“Only through the concrete understanding of particular worlds of suffering and the way they are shaped by political economy and cultural change can we possibly come to terms with the complex human experiences that undermine health”

Kleinman (1991).

Chapter 3: Methodology

3.1 Introduction

The main study objective conveys that a complex phenomenon is under investigation; interpretations and local lived experience of two EVD outbreaks that captured ‘global’ attention and the contextual realities during and in the periods outside of external intervention. Exploring these issues requires a deeper understanding lending itself to employing an interpretivist approach to inquiry. In this study an understanding or interpretation of the lived experiences and the contextual realities of two EVD outbreaks in western Uganda emerged from the analysis constructed from the participants perspectives.

3.1.1 Research Methodologies in Global Health

Quantitative research has contributed greatly to global health research and provides data in terms of neat figures. Programs such as the Global Burden of Disease (GBD), used to guide the WHO on more effective implementation of strategies for disease control and prevention worldwide, provide volumes of quantitative information and statistical findings. The main health metric used to measure the burden of disease is the disability adjusted life year (DALY), which objectively quantifies the burden of disease and hence informs policy makers of what is going on in the world. Policy makers tend to favour having quick access to tidy figures on life expectancy, birth rates, and HIV prevalence to make decisions as well as for measuring health outcomes such as vaccination coverage. However, numbers hide far more than they reveal, and by disregarding the meaning behind the numbers, a deeper understanding of underlying health outcomes can be lost.

What cannot be counted simply doesn't count, and so we systematically ignore large and important areas of concern (Hoos, 1979).

For this reason the contribution of qualitative research also requires consideration in global health and its use in complementing quantitative measurement by looking at issues from a deeper perspective. Qualitative research also gives voice and context to those who have

experienced illness and disease. This is important in a world where the majority of social concepts and theories are generated from external perspectives.

3.1.2 Qualitative Research in Ebola Outbreaks

As discussed in chapter two the initial review of the extant literature revealed that the majority of research studies carried out on EVD outbreaks were epidemiologically focused and from the positivist perspective, and few concerned themselves with the qualitative paradigm (de Roo *et al.*, 1998; Hewlett & Amola, 2003; Hewlett & Hewlett, 2008, Kinsman, 2012; Matua 2014).

Over the last decade, there have been numerous discussions from within the social sciences critiquing the narrative framing of ‘emerging infectious diseases’ and the underlying rationale of international involvement leaning towards the theoretical perspective of political realism (Bass, 2009; Fidler, 2005; Farmer, 2009; Leach & Dry, 2012 and Scoones, 2010). Since the West African EVD outbreak, there have been numerous additions to these discussions particularly from the perspective of geopolitics (Horten, 2015, Larkan *et al.*, 2015) and critiques of international response mechanisms (Gostin & Friedman, 2014, Kalra *et al.* 2014). However, a paucity of knowledge remains that is inclusive of local perspectives or ‘southern theories’ using a qualitative research approach.

3.1.3 Researchers Position

It would be a misrepresentation to assume that the researcher entered into the study value free from the discourse and personal experience of the phenomenon under study.

According to Maxwell, (2005) traditional thinking holds that the researchers background and identity in the research have been seen as a source of *bias* and something that needs to be eliminated as much as possible. In qualitative inquiry, however it is accepted that the researcher is the primary instrument of data collection and analysis relying on skills and intuition that filter through an interpretive lens.

The most admirable scholars within the scholarly community [] do not split their work from their lives. They seem to take both too seriously to allow such

dissociation, and they want to use each for the enrichment of the other (Mills, 1959, p. 195).

The explicit incorporation of the researcher's identity and experience in the research has gained wide theoretical and philosophical support (Berg and Smith, 1988). The researcher's position from the onset of this study can be best understood from the following account:

The researcher originates from a background in veterinary medicine with an interest in public health and development. Pursuing an MSc in Global Health between 2009 and 2011 at Trinity College Dublin, Ireland resulted in a study focusing on the One Health concept. This interdisciplinary phenomenon of understanding health challenges across the human-animal-environmental interface was undertaken in Eastern Rwanda in 2011, linking veterinary medicine to global health. Following graduation, the researcher remained based at the University of Rwanda from where she continued with her PhD. Her original PhD proposal again focused within the area of One Health and Global Health. From 2011, the Department of Veterinary Medicine at the University of Rwanda (formerly Umutara Polytechnic) became a recipient of a ten-year bi-lateral donor-led initiative called One Health East and Central Africa through the United States Agency for International Development (USAID) Emerging Pandemic Threats Program. The initiative involved 14 institutions including schools of public health and veterinary medicine and the ministries of agriculture and health across six countries in the east and central African region (DRC, Ethiopia, Kenya, Rwanda, Tanzania and Uganda). Being located at the University of Rwanda for over five years allowed the researcher access to participate in a number of the project activities and attendance at two One Health conferences within the continent. This opportunity gave the researcher a unique perspective, a position not commonly experienced by the majority of 'northern' researchers. This internal perspective directed the researcher's interest towards looking at the concept of 'southern theory' or 'theory from the south' as outlined in the writings of Connell (2007) and Comaroff (2012). Southern theory puts forward the idea of inverting the position of western enlightenment or theory as universal learning and therefore enabling the global south a position to express theoretical insights into how the world works. This 'theory from the south' directed the researcher towards looking at how 'emerging infectious diseases' as a global health phenomenon are experienced and locally understood. Even before the West African outbreak, the researcher had identified EVD epidemics as an interesting context in which to examine the phenomenon of 'southern theory'. This became the area of focus for the

doctoral thesis. Following her initial experiences, reading around the literature, discussions with her supervisor, an anthropologist, and attending a number of international Conferences; a concept developed around how emerging infectious diseases were being constructed as ‘crises’ in global health. Her location within the East African region directed her towards looking at local interpretations of EVD outbreaks as global health ‘crises’ and the periods outside of these crises as an interesting area for analysis. Therefore capturing a ‘southern theory’ would require an interpretivist approach to the study within the qualitative paradigm outlined above.

The area was relatively stable on the Ugandan side of the DRC border up to the time of the research. The researcher was aware that Bundibugyo’s proximity to the DRC border was a potential conflict affected areas and attempted as much as possible to keep updated through media reports in the national and regional media, Embassy updates and have a good background of the context from the available literature. An incident did occur in Bundibugyo town on 5th July 2014, one week before the initial site visit where 85 people were killed during a rebel attack on police barracks (BBC, 2014). There was heavy military presence in Bundibugyo town during the period of data collection.

3.1.4 Philosophical Foundations of the Study

The epistemological stance taken by the researcher in this study is non-positivist where she believes that both facts and values are intertwined in the generation of scientific knowledge. This is a qualitative study set within the constructivist, interpretive paradigm that employed a phenomenological approach where the researcher sought to understand the context and meaning of the participant’s experience during and in the aftermath of two Ebola outbreaks. Figure 3.1 outlines the theoretical assumptions and methodology employed in the study.



Fig. 3.1 Theoretical Assumptions and Methodology

The ontological stance taken in the study (the researchers concept of reality) is that reality is an inter-subjective construction of the shared human cognitive apparatus. In other words, this is the researchers account of how she interpreted the participants experience and meanings on two Ebola outbreaks.

What we call our data are really our own constructions of other people's constructions of what they and their compatriots are up to (Geertz, 1973,p. 9).

Van Maanen (1979) refers to participant construction as first-order concepts and the constructions of the researcher second-order concepts. Gertz (1973) argues that interpretive research is not about answering the deepest questions about other societies but merely to make interpretations of these societies available in the literature. Therefore, the interpretive paradigm was considered the most appropriate approach to give voice to those who had experienced EVD outbreaks in western Uganda.

3.2 Study Design

Qualitative case study design was selected as the most suitable methodology to meet the four study objectives as it functioned to capture the lived experiences from a variety of perspectives and within context. As described by Baxter and Jack (2008) case study design

allows exploration through a variety of lens allowing multiple facets of the phenomenon to be revealed and understood.

3.2.1 Case Studies

In this study case study was used as the tool of interpretive investigation where several visits to the field occurred over an extended period. Case study refers to the intensive study of a single individual, group, unit, or event. According to Yin (1984, p.23)

“Case studies are a strategy for doing research, which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence.”

This was a multiple case study where the researcher selected two EVD outbreaks that occurred in Bundibugyo and Kibaale Districts in western Uganda in 2007 and 2012 respectively. Each of the two case studies focused on the lived experiences of a group (the community) within a unit (the health system) surrounding an event (an EVD outbreak).

Explorative case study is used when a complex phenomenon is studied in order to gain a deeper understanding about its nature (Bengtsson, 1999). Yin (2009) expands this rationale by supporting the view that the distinctive need for carrying out case study as a research method arises out of a desire to understand complex social phenomena, and to explain causal links too complex to be answered by quantitative methods (Yin, 2009). Employing a case study design was therefore appropriate to explore both EVD outbreaks from an interdisciplinary perspective discussed in chapter two (Section 2.5.1).

Using case studies also provided a focus to guide the researcher to identify the type of data and the participants who could best provide that data. For example patients and health care workers, some of whom became patients following infection, were identified as the best source of insight into the lived experience of the EVD epidemics. District health officials, hospital management and ancillary staff involved in the outbreaks provided another source of data on lived experience and interpretations of the outbreaks and the external interventions outside of the isolation units as events unfolded around them.

According to Robson (2011), case studies have been open to criticism in the past as a strategy to the advancement of knowledge from the positivist view of science considering them a ‘soft option’ or a flawed experimental design when compared to experiments and

surveys. However, more recently they are viewed as a fundamentally different research strategy with their own designs and application.

Case studies are presented as a rich narrative that is interesting and insightful to the reader. When using case study design the researcher must describe what they observe and what they do not observe but interpret. This requires the researcher to have a creative insight and be well able to build a logical argument around an explanation. When using case studies they should be individually evaluated for their standards of rationality (Robson, 2011). It is the objectives and intentions of the study, and the specific methods used that are of most concern. Data triangulation is essential and therefore the case study warrants various sources of data that must converge to be valid.

3.2.2 Rationale for using two Case Studies

Findings from case studies are not considered strong enough to be generalizable to the larger population (Yin, 1994). However, it is claimed that where similar findings emerge from multiple case studies the conclusions are more robust because the results can be compared and contrasted (Robson, 2011; Yin 1994). Factors that limit the number of cases that can be included in a multiple case study include cost, ethical constraints, and the availability of the natural phenomenon. EVD outbreaks are relatively rare when compared with other infectious disease outbreaks such as cholera but Uganda has experienced five outbreaks since 2000. To strengthen the validity of the findings and taking into consideration available funds and time, the researcher chose two of these five case studies as a realistic objective. The two case studies chosen were Bundibugyo 2007 and Kibaale 2012 because they were the second and third largest outbreaks that occurred in Uganda and had not been explored previously from a qualitative perspective. The first and largest outbreak in Gulu district in northern Uganda has been documented from both an epidemiological and an anthropological perspective (Hewlett and Hewlett, 2003; Kinsman, 2012). During this study, however findings from a phenomenological study on the Kibaale 2012 outbreak were published (Matua, 2014). The two remaining recorded outbreaks in Uganda included a single case fatality in Luwero district in 2011 and a second outbreak that occurred in Kibaale in 2012.

3.2.3 Selection Rationale

According to Bengtsson (1999) multiple case studies can be selected for *literal* or *theoretical replication*. *Literal replication* cases are selected because the cases and results are predicted to be similar. *Theoretical replication* refers to cases that are selected because the cases and predicted results contradict each other. The cases in this study were selected under *literal replication* as both cases involve the experience of an EVD outbreak on the community within a public health system in western Uganda. This is referred to as a general explanation model where certain characteristics are shared by both cases, even though the cases also vary in detail (Bengtsson, 1999).

The first case study selected was in Bundibugyo district in western Uganda where an EVD outbreak caused by *Ebola Bundibugyo* occurred in 2007. The second case study chosen was located in mid-western Uganda in Kibaale district, where an EVD outbreak caused by *Ebola Sudan* was managed in the town of Kagadi in 2012. The characteristics shared between the two case studies include contexts that demonstrate an array of similar social determinants including extreme poverty, a fragile health system, neighbouring conflict, displaced populations, and a burden of endemic disease. Shared characteristics also included the infrastructural capacity and resource scarcities within both hospitals at the centre of the outbreaks. Both cases included a district general hospital where the EVD outbreaks were managed. Both hospitals were built during the same era, were similar in design and construction, and shared similar resource challenges. Apart from ongoing historical land issues outlined in section 2.3.4.2, Kibaale district is relatively stable but shares similar levels of poverty, rural isolation, endemic burden of disease and population burden with Bundibugyo. Kibaale also hosts a refugee population from eastern DRC and has the highest fertility rate in Uganda.

Details that varied between the two case studies include timing in relation to the geopolitics of the outbreaks. The International Health Regulations revised in 2005 were ratified in 2007, the year coinciding with the Bundibugyo outbreak. In theory, this meant that all WHO member countries including Uganda were mandated to possess suitable surveillance and response systems, despite no funding being made available. 2007 also marked the year when Uganda hosted the Commonwealth Heads of State General Meeting (CHOGM) between the 23rd and 25th November in 2007. This allowed consideration for how this politically important event may have influenced delays in announcement and response to the outbreak.

The EVD outbreak in Kibaale occurred five years following ratification of the 2005 Revised International Regulations in 2007. By this time, Ebola had become more recognised on the global health agenda. By now the narrative of ‘emerging infectious diseases’ was well established and available funding for responding to such outbreaks was more explicit. As a result, the 2012 Ebola outbreak was rapidly diagnosed and responded to, bringing it under control within three months of its emergence in July 2012. Focusing on the interim, intervention and aftermath periods of both outbreaks allowed for exploration of the broader context of EVD outbreaks not normally captured during outbreak reports.

As explained in the previous section a number of constraints can limit the number of case studies chosen in a multiple case study including the availability of cases, funds and time available including ethical considerations. These practical and logistical factors were also employed when choosing the two case studies used in this study. The researcher was based at a university campus in northeastern Rwanda where the research sites could be reached by road either directly or via Uganda’s capital, Kampala. Bundibugyo is located 363km west of Kampala via the Fort Portal highway (A109) and construction of a new road between Fort Portal and Bundibugyo was completed in 2014. Bundibugyo can be reached from Kampala in less than seven hours. The town of Kagadi in Kibaale district can be reached via a non-surfaced road within one hour from the town of Kyenjojo along the Fort Portal highway. The researcher also had a co-supervisor based at Makerere University School of Public Health. Logistically the researcher used a loop from Nyagatare in Rwanda, to Kampala, Uganda and from Kampala to Bundibugyo diverting to Kigadi town in Kibaale district on the return trip to Kampala.

3.2.3.1 Bundibugyo

Bundibugyo is located in the extreme west of Uganda bordered by Lake Albert and Hoima district to the northeast and the DRC along its western border. Bundibugyo became a district in 1974 having been traditionally part of the Kingdoms of Toro and Kabarole. It is the only Ugandan district isolated west of the Rwenzori mountains and is both geographically and culturally part of central Africa, despite being politically within East Africa. Construction of a new road between Fort Portal to Bundibugyo and Lamia was completed in 2013 making Bundibugyo town more accessible.

The population of Bundibugyo according to the 2014 national census was estimated at 224,387 and 79% of the population are under 30 years (UBOS, 2017). Eighty eight percent of the population of Bundibugyo is engaged in crop growing. The main crops grown are coffee, cocoa, beans, rice, cassava, matoki, and vanilla. According to Uganda Bureau of Statistics (2009), Bundibugyo has 34 health units serving a population of over 200,000 (Figure 3.2). The doctor to population ratio is approximately 1:70,500. The most commonly reported causes of ill health and mortality are malaria at 68.4%, respiratory diseases at 12.5% and diarrhoea at 6.9%. HIV is reported at 0.1% but is likely to be under reported. Infant mortality is 102/1000 births and maternal mortality is 505/100,000 births.

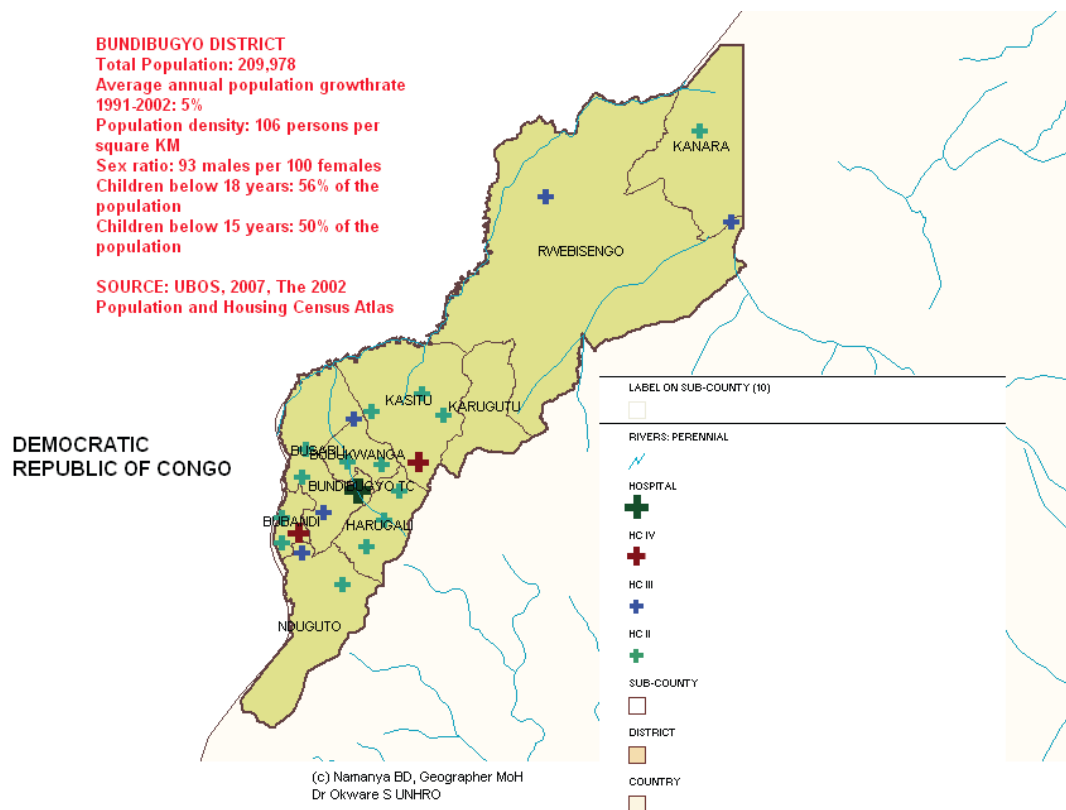


Figure 3.2: Health Facilities in Bundibugyo District, Western Uganda

(Source: Okware, 2015)

Bundibugyo district has experienced a long history of conflict and is particularly affected by events in neighbouring DRC. For example on the 5th of July 2014, a week prior to data collection, a rebel group stormed the town of Bundibugyo directing attacks on the police force and military barracks and a total of 85 people were killed (BBC, 2014). Previous

attacks in the area occurred between the Allied Democratic Forces (ADF), an anti - Ugandan government rebel group supported by the government of Sudan who fought the government of Uganda during the Sudan 2nd civil war (1983-2005). In the 1990's, tens of thousands of local civilians were displaced by ADF insurgents and in 2007, intense battles between the ADF and the Ugandan military occurred inside the Semuliki National Park close to Bundibugyo town. In 2013, resurgence of the ADF in eastern DRC displaced over 60,000 refugees from DRC into Bundibugyo, putting excessive pressure on an already weak health system.

An EVD outbreak was officially announced on 29th November 2007 following a suspicion of an unknown disease that was first reported in June 2007. The Bundibugyo case study involved three study sites: Kikyo Health Centre IV, Bundibugyo General Hospital and the District Health office, which were the main sites from where the outbreak was managed. In total 132 cases were reported and 42 people died during this outbreak. The last case was reported on the 3rd January 2008 and the outbreak was declared officially over on the 20th February 2008.

3.2.3.2 Kibaale

The second case study is based in Kibaale District in Midwestern Uganda bordered by Lake Albert to the west, Hoima district to the north, Kiboga district to the east, and Mubende District to the south. Kyenjojo, Kabarole, and Bundibugyo districts border the southwest of Kibaale district (Figure 3.3).



Fig. 3.3: Kibaale districts south east of Lake Albert

Kibaale district was created from Hoima district in 1991 and consists of 3 counties, 18 sub-counties, and 2 town councils. Uganda Bureau of Statistics (2009) conveys that the mainly rural population of 582,000 is mostly engaged with subsistence crop production (UBOS, 2009). The population growth rate is 5% with 51% being female. The population density increased from 20 persons per square kilometer in 1969 to 98 in 2002. In the 2002 consensus 88.2% of the population, live in temporary dwelling units (mud and wattle houses with thatch or iron sheet roofs). Only 0.4 % of households have electrical light, 64% latrine coverage and only 5% have access to hand washing facilities. The district lacks surfaced roads.

There are 34 public health unit facilities in Kibaale district. The doctor to population ratio is 1: 42,000. Life expectancy is lower than the national average at 49.1 years. Malaria accounts for over 40% of reported morbidity, acute respiratory disease for over 20%, anaemia 8%, intestinal worms 5.5% and a HIV prevalence of 6.4% is reported (UBOS, 2009). Infant mortality rates are 75/1000 births and maternal mortality rates are 435/100,000. Contentious ethno-political instability has frequently surfaced in Kibaale District, referred to in chapter two (Section 2.3.4.2) as part of the “Lost Counties” issue.

An EVD outbreak was declared on 28th July 2012 resulting in 17 fatalities out of 24 cases, 12 of these deaths occurred within one family. The outbreak was officially confirmed over

on the 24th August 2012. A total of 13 probable, 11 confirmed cases and 17 deaths were reported during this outbreak (WHO, 2012b).

3.2.4 Theoretical Sampling: study participants

According to Bowling (2009) the aim of qualitative analysis is to understand complex phenomena and to generate hypothesis, rather than to apply the findings to a wider population. Therefore, in this study non-random sampling or theoretical sampling methods were employed. Theoretical sampling refers to how cases and the participants within those cases were chosen for theoretical and not statistical reasons, a method used in qualitative studies. According to Eisenhardt (1989), it makes sense when trying to understand a phenomenon to choose cases and participants that are of particular interest, or represent extreme situations and polar types in which the topic of interest is transparently observable. Such cases are likely to contribute to the emergent theory, by either supporting existing theories or bringing new perspectives to allow extension of an existing framework. This is also referred to as purposive sampling because the researcher actively seeks out each participant. In some cases, the researcher will seek out the next participant based on a need to expand knowledge on a concept from a previous interview. This study adopted this purposive sampling strategy aimed at targeting those identified as having particular knowledge that could give a deeper insight into the cases under review. Respondents were purposefully chosen based on the main objective of the study. A cross-section of participants was included to capture a variety of perspectives required under case study design. These respondents were identified as the survivors; those employed within or service users of the health units from the communities where both outbreaks were experienced. Specific subgroups were identified for interview and these included district officials, hospital management and non-medical staff working in administration, surveillance, diagnostics and logistics. Medical staff included health care workers some of whom were infected by the virus and became patients themselves. Patients from the communities and their families who were directly affected by the outbreaks were also included. Snowball sampling was sometimes used in this study as some participants identified as key informants had changed positions but were still residing and working within the district. One of the participants was semi- retired, one had transferred from the hospital to the district level, and three had been transferred to other health centres in the district since the outbreaks. Location of some patients and family members from the

community were also identified and sourced through the health workers interviewed. The study included 25 participants, 13 from Bundibugyo, and 12 from Kibaale district.

The sample included 13 health workers, 7 hospital ancillary service staff, 3 district health officials, and 2 community members. At the time of data collection, all participants resided within either of the two districts and 22 of the 23 health service employees were still employed within the Ugandan health services. For all study participants this had been their first experience of an EVD outbreak. Participants were aged between 35 and 65 years including 6 females and 19 males (Table 6, Table7).

Table 3.1: Participant Demographics (n=25) & Work Locations at Time of Ebola Outbreaks

Variable	Participant Data
Age range	35-65
Gender (male, female)	19, 6
<u>Work location at time of 2007 Ebola outbreak</u>	
Health Centre IV	4
District General Hospital	17
District Offices	2
Community Members	2

Table 3.2: Participant Positions & Outcomes at Time of Ebola Outbreaks

Positions at time of Ebola outbreak	
Health Care Workers	13
Administration, Ancillary, Technical staff	7
District Administration	3
Community Members	2
Time in position at onset of outbreak, mean (years)	1-30

Worked in direct contact with Ebola patients	8
Infected with Ebola through patient contact	5
Lost a direct relative, colleague or friend to Ebola	9

3.3 Ethical Considerations

3.3.1 Process of Application for Ethical Approval

Ethical application for the study was initially submitted to the Health Policy & Management/Centre for Global Health Research Ethics Committee at Trinity College Dublin, Ireland in August 2013. Following amendments, the revised application was granted approval on 6th March 2014. Simultaneously ethical permission was also under process from the Institutional Review Board (IRB) at Makerere University School of Public Health (MUSPH), Uganda. This was granted on the 31st March 2014.

University ethical clearance was followed by a second step to the ethics procedure in Uganda that included submission of the proposal to the Uganda Institute of Science and Technology. Final approval for research clearance was sought from the Presidents office. This was granted on the 25th June 2014.

3.3.2 Access

The researcher travelled to Bundibugyo town, Kikyoo village and Kagadi town in Kibaale district on the week commencing 14th July 2014. The purpose of this initial visit was first to present the research clearance letter from the Office of the President of Uganda to the Resident District Commissioner in Bundibugyo and Kibaale districts. Secondly the researcher initiated introductions at the district health offices and health facilities where the outbreaks were managed in 2007 and 2012 respectively. In Bundibugyo town the researcher presented herself to the district health officer at the Ministry for Health district office. The district health officer who was recently appointed to Bundibugyo identified two participants as potential key informants as both had been actively engaged during the EVD outbreak in 2007. Having made initial contact by telephone both potential participants met with the researcher to discuss the project and agreed to partake in the study. Both were

given a participatory information leaflet (PIL), a copy of the consent form and the contact number for the researcher and the IRB.

From here the researcher moved to Bundibugyo General Hospital where she introduced herself to the medical supervisor to discuss the study. The medical supervisor also recently appointed to Bundibugyo contacted one of the nurses who had been involved in the outbreak in 2007 and requested her to assist with identifying colleagues in the hospital who experienced the outbreak. The names and contacts of colleagues were written on a sheet of paper and the nurse accompanied the researcher to the various wards, departments and living quarters to locate the identified individuals in person. Again the researcher explained the purpose of the research study, when the interviews were estimated to take place and answered any questions in relation to the study. Copies of the PIL and consent forms were dispersed with each encounter and contact details for the researcher and IRB chairperson were provided to potential participants.

The medical supervisor and nurse at Bundibugyo General Hospital gave directions to the researcher to Kikyoo Health Centre IV where the initial cases of the outbreak in 2007 were managed. Kikyoo was in an isolated rural location approximately one hour drive into the Rwenzori mountains on an unsealed road from Bundibugyo town. Here the researcher introduced herself and the study to the nurse in charge of the health centre who had also experienced the outbreak in 2007. From here the researcher was given further directions to Nauka Health Centre II, about 20 minutes past Kikyoo where two of the nurses who had experienced the outbreaks at Kikyoo were transferred since the outbreak in 2007. The researcher continued to this rural health centre and again made a formal introduction and discussed the study with the potential participants. Again the PIL and a copy of the consent forms were submitted to the potential participants.

A similar procedure was followed at Kibaale General Hospital in Kagadi town, Kibaale district where potential participants were identified through the medical supervisor and senior nursing supervisor as gatekeepers to the participants. Again a verbal and written description of the research, copy of consent forms and answers to questions about the study were provided to a variety of potential participants. The participants who were willing to take part were given an estimated date during which the interviews would take place.

All potential participants identified during the introductory stage were again contacted by the researcher by telephone prior to the interview phase of the study to inquire if they wanted to participate in the study. The researcher emphasised to each of the potential

participants during these follow up calls that they had the right to refuse participation and to withdraw from the study at any point without explanation.

All participants who agreed to participate were requested for a day, time and venue that suited them for conducting the interview during the interview phase of the study. No coercion or deception was used to attract participants to partake in the study. The researcher was asked by some potential participants how the research study would be of benefit to them. This was a reasonable question considering that the researcher was a foreigner. The overall purpose and perceived benefits of the research findings were outlined to them verbally and by provision of the PIL. Management at both hospitals supported the idea of the research study as the researcher had highlighted the importance of the study in terms of giving voice to the healthcare worker's experiences of the outbreaks as interpreted from their perspectives. In addition the value of the study in terms of informing future policy on lessons learned and as a contribution to future preparedness was also outlined.

3.3.3 Informed Consent

The purpose and process of consent was explained to each of the potential participants during the initial site visit and the participation information leaflet (PIL) was left with potential participants to read and refer to during the interim period (Appendix F). The contact telephone number and email address of the researcher was included on the PIL and the contact telephone number of the MUSPH Institutional Review Board chairperson was also provided on the consent forms (Appendix F). The contact number of key informants was taken and potential participants were contacted after ten days to enquire if they wished to participate in the research study and if they were willing to give consent in a written or visually indicated form. Consent was obtained prior to each interview and another opportunity to ask questions relating to the interview process and the study in general was given before and at the end of each interview. In one case where the participant was illiterate a relative signed consent on their behalf and in their presence.

Each participant was again reminded that they were free to withdraw from the study at any time without explanation. Signed consent forms were retained by the researcher and kept in a locked cabinet within a locked room at her home.

3.3.4 Participant Anonymity

All details identifying participants following data collection were made anonymous. Each interview was allocated an individual case identity number at the start of each recording that was aligned with the front page of the questionnaire. For example the 1st interview on the 23rd July was assigned the number 230701 on the questionnaire sheet used by the researcher and assigned to the file name on the audio recording. Apart from responses, no personal details were stored with the audio recordings or on the questionnaire that identified the participant. A list of the participant's identification details linked to the individual case identification numbers were not kept with the questionnaires but in a separate place under the sole access of the researcher. The researcher was the sole person who recorded the interviews and had subsequent access to the audio recordings.

3.3.5 Data Storage

At the end of each day the researcher listened and uploaded the interviews onto a VMA file and stored them in a logical order assigning a participant number which related to the date and interview as described above. All hardcopies of participant details, questionnaires, and the audio recordings (transferred to a hard drive) were kept in separate storage units in a locked room at the researcher's place of residence. Participant details linking audio transcripts and hard copy questionnaires were saved electronically onto separate files and both files were encrypted using the software package *True Crypt* and password protected, in case of theft. A password was created for accessing the two files where the interviews for each case study were stored. The computer was only accessible via the researcher's personal log in details and password. One encrypted and password protected backup copy of questionnaires and the participant details were stored in a cloud file. This served as a backup in case of theft of the researcher's laptop computer.

3.3.6 Managing Risks and Benefits

There were no criminal or other disclosures that required action identified during the data collection period of the study in relation to interviews or observations.

Some participants found the experience distressing as talking in depth about the loss of family members and colleagues brought up feelings of sadness and anguish. One

participant became emotional when describing a family member who died during the outbreak. Another health care worker who initially fled the hospital where patients were being treated for fear of being infected appeared embarrassed. Another participant infected during the outbreak displayed some anguish in conveying the experience of imminent death. In several cases participants conveyed their experiences through humour which may have been used as a means of self-preservation to mask distress caused by relaying difficult events. For those who experienced anguish during the interview, the researcher requested if they needed some time before continuing with the interview or if they wanted to postpone or withdraw from the interview. All expressed that they were comfortable to continue. A request for a local counselling service for participants who wanted to confide in a confidante over any disturbing issues that emerged during the interview was discussed with the hospital supervisors during the introduction stage. The researcher emphasised to the participants that their identities and audio recordings were kept in the sole charge of the researcher and under strict confidentiality. They were also informed that under no circumstance would the raw data be shared with any other person including other members of staff, supervisors or MoH officials.

3.4 Methods of Data Collection

In the study, data was collected using three qualitative research methods: in-depth interviews, document analysis, and direct observation. Field notes and memos were also used and formed part of the data set.

3.4.1 In-depth Interviews

The method that extracted the largest volume of data in the study was the in-depth interview. In-depth interviews are an important method within the constructivist paradigm as they allow a mutual partnership of meaning to develop between the researcher and the participant. The interviewer is in a position where they can probe deeper into certain areas to develop a better understanding of the meanings the participant accounts to their views of reality. According to Mills *et al.* (2006), undertaking constructivist enquiry requires a position of mutuality between the researcher and the participants in contrast to being an objective observer.

The in-depth interviews were guided by semi-structured questionnaires (Appendices A to E). Interviewing is the most common method of data collection used in qualitative research and semi-structured questionnaires are used extensively as an interviewing tool for individuals or groups (Jamshed S. (2014)). One of the primary values of using semi-structured questionnaires was that it allowed flexibility to add or subtract questions depending on the results from a previous interview. New issues were sometimes added throughout the course of the interview process and the order of the questions varied depending on the direction of the discussion. This semi-open method allowed participants to introduce issues for discussion, that the interviewer might not have considered. For example, the concept surrounding what motivated some health care staff to remain on site when the majority of staff and patients had abandoned their posts out of fear emerged as an additional area of enquiry that emerged during the interview process.

This was a phenomenological study that drew on the lived experiences of the participants therefore it employed a design that required a limited number of open-ended questions with minimal structure. However as evidenced by the questionnaires in appendices A-E it appears that many structured questions were asked for each of the various groups. The reason for including a number of more structured questions was related to gathering the data required to answer the first objective of the study that sought to understand the contextual realities from where the EVD outbreaks emerged. In each of the case study sites, there was more than one institution where the EVD outbreaks were experienced and managed by the participants. In Bundibugyo for example a health centre, IV and a general hospital managed the outbreak in 2007. In Kibaale, the general hospital in Kagadi town managed the outbreak in 2012. While all of the questions are included in the questionnaires in appendices A-E, not all were asked during every interview. The structured questions relating to the physical resources and health challenges were used in only two or three of the initial interviews at each of the study sites. These were targeted mostly at the hospital management and senior health care workers in an attempt to understand the contextual background within the different health units before, during and in the aftermath of the outbreaks. These structured questions provided information about the physical environments and resources available at the time of the outbreaks. As described below in section 3.4.2 direct observation by the researcher within these health units was used to compare these accounts with what she observed during the interview phase.

Conducting all of the interviews personally with the participants had both advantages and limitations. First, it allowed the researcher to exist within the study, to memorise the

participant and the context when listening to the audio recordings at a later stage, to ensure a systematic approach was followed and to control the flow and direction of the interviews. Limitations of this approach included researcher effect, where the researcher, as an outsider, may have been interpreted as someone who had alternative motives, self-interests or came from a position of power. To mitigate this effect each interview concluded with an invitation by the researcher for the participant to ask questions about any of their concerns about the interview or the study in general. A common question asked was what was the purpose of the study and how would it be of direct benefit to the participants. The researcher answered all questions to the best of her ability and reminded the participants that she was available to answer any further issues by telephone or email as detailed on the PIL. Media coverage of the West African Ebola outbreak was occurring at the time of data collection. Some staff in the hospitals assumed that the researcher was seeking to recruit people or may have had more information about the possibility of an imminent outbreak and was interested in the current capacity to respond. One phone call to the researcher about a month following the data collection phase was to enquire about a position to work in West Africa, which supported this perception.

English is spoken by the majority of personnel working within health systems in western Uganda, and among some community members. An interpreter was required only once during the data collection phase to interview a family member of Ebola victims. This allowed the researcher to conduct all of the interviews personally using an audio-recorder and eliminated the need to select and train translators.

English was chosen for the interviews on practical grounds because the mother tongue of the study participants varied as they originated from a variety of tribes across Uganda. English is used as the common language shared between tribes in Uganda and the official language used in educational and public institutions. As mentioned above English allowed the researcher to conduct each interview in person within the financial and time constraints available. The limitations with using English in the study are outlined in section 7.4.2.3.

The data collection for the study took place in 2014. The researcher drove her own vehicle which was essential due to the difficulty accessing various sites such as Kikyoo Health Centre IV and Nauka Health Centre II in the Rwenzori mountains in Bundibugyo district, and reaching rural based communities where families and patients from the outbreak resided in Kibaale. The study also took place during the long rainy season and roads were sometimes difficult to access. During the interview process the researcher lodged in local

hotels and guest houses in Bundibugyo and Kyenjojo districts. Living in the context of both study sites during the data collection period gave an added insight into the communities particularly from a socio-economic position.

The majority of participants were interviewed within the health care settings where they worked following clinics or during quiet periods. Interviews were conducted in a private setting such as an office, consultation room or a laboratory. This was advantageous as it gave the researcher access to simultaneously observe the context under study. It was also efficient for both the researcher and participants in terms of accessibility, time, and costs. However, some of the limitations with this approach were that interviews were occasionally interrupted, physically or by telephone and complete privacy was not always granted. District officials and one doctor were interviewed in a quiet area of a local hotel, which allowed for better privacy and less distractions. The interviews commenced with general questions to relax the participant and obtain a brief background to their current positions and length of service duty. The participants were then asked to recall the period before the outbreaks, in terms of the infrastructural, human, and financial resources available before the outbreaks. The purpose of this was to construct the context in which the outbreaks emerged in the mind of the researcher. This picture was supported through direct observation at the time of the interviews and used to compare it with what was described during the interim and intervention periods of the outbreaks.

The next section moved onto the EVD outbreak and questions were less structured to allow the participant to openly express their experiences and understandings of events. The researcher maintained the flow of the interview by probing deeper to vague responses or by asking for a clearer explanation when needed. Notes were inserted on the environment, body language, tone, and mannerisms of the participants in the questionnaire margins.

Interviews ranged between 40 minutes to one and a half hours. All interviews, except one were conducted in English. In that case, another participant who assisted in identifying the community member translated for the researcher. All interviews were audio-recorded except one where the participant declined because she did not entirely trust the promise of confidentiality. In this case, the researcher recorded the answers by taking brief notes. Unlike audio-recordings where the researcher had the advantage of transcribing at a later stage, the researcher revisited the notes immediately following the interview to ensure that gaps were filled. In addition to in-depth interviews other qualitative methods used to gather

data during the data collection phase included non-participant observation, document analysis and field memos.

3.4.2 Non-Participant Observation

In this study direct observation of persons at the study sites other than the participants who gave informed consent for interviews was excluded. As this was not an ethnographical study neither sufficient time nor ethical approval was sought for direct participant observation. The observation used in this study was focused on non-participant observation.

According to (Merriam & Tisdell, 2015) observation is advantageous as it allows the researcher to gather information about a process, an event or facility within the environment where the phenomenon of interest naturally takes place and can capture unplanned events. This method of data collection strengthens the ecological validity of the findings because it is non-invasive. Ecological validity refers to the extent to which research can be generalized to real life situations (Ashcroft, 1994). Observation as a single source of data collection is limited because the observer cannot interfere with active clarification of the findings. In most studies, observation is used as a complementary data collection method to support triangulation and theory generation (Eisenhardt, 1989). In this study, data observation was used to achieve triangulation when combined with interviews and documentary analysis.

Non-participant observation was an important method of data collection in this study because it contributed towards answering the first and fourth objectives. In support of the first study objective (*what are the contextual realities of Bundibugyo and Kibaale from where two Ebola outbreaks emerged in 2007 and 2012 respectively?*), observation contributed objective data towards understanding the physical geographical, environmental, socio-economic and political contexts of both study sites. In support of the fourth objective (*What were the determinants and consequences of global health interventions during and in the aftermath of the Ebola outbreaks in Bundibugyo and Kibaale?*) non-participant observation provided data to explore the aftermath of external interventions in terms of health system strengthening at the time of data collection. For example, observations of physical infrastructural resources provided information on improvements, if any of current health systems in terms of capacity to respond to future outbreaks.

Similar to the interviews, observation as a data collection method in the study was conducted solely by the researcher. This allowed the researcher to visualise the setting during the outbreak and observe the current situation and context where the outbreaks occurred. During the introductory phase, for example the researcher visited some of the living quarters of the hospital staff to contact potential participants in Bundibugyo. This assisted in observing events later described in some interviews during the outbreak when few staff remained at the hospital and concepts of isolation and social cohesion between colleagues and neighbours emerged. These direct observations were sometimes captured in notes written in the margin of the questionnaire or recorded following interviews in a notebook.

Non-participant observation was carried out during the same period in which the interviews were conducted. By conducting every interview, the researcher had a walk-through opportunity to simultaneously observe the context by gathering objective information simply and directly from the immediate physical environment. This skill to interview while directly observing the context was well developed in the researcher's field experience as a veterinarian, where history-taking and visual examination, listening and observing are conducted simultaneously in the process of arriving at a tentative diagnosis. This was important because the majority of the interviews were conducted on the sites where the EVD outbreaks occurred, in the clinics, hospitals, and district offices and in one case at the home of an index case family. Many of the participants obliged by giving the researcher a visit of the health facility sites before or following the interviews where the participant was available for clarifications. This began as a pilot phase from the first time the researcher traveled to the two study sites before conducting the interviews.

Using the introductory visits as a pilot phase for non-participant observation allowed the researcher to develop a structured approach to collecting information during the data collection phase. The pilot phase allowed the researcher to identify a number of broad categories of observations that emerged in Bundibugyo and then repeated these in the Kibaale study site. The two main categories of data used to support the study objectives included observations on the context of both sites and observations relating to the physical health system resources within the health facilities at the time of data collection in 2014. Subcategories relating to context included geographical features such as the distance of the study sites from the nearest metropolis, access to the sites including road surface and modes of transport, land usage, climate and topography. Socio economic observations captured housing structures, types of businesses and industry, religious and educational

institutions, and general demographics such as volume of people, gender, ages, and activities. Socio-political observations included the presence and type of security forces in the area and evidence of local governance. As mentioned above several observations relating to the health systems were carried out simultaneously to the interview process.

Empirical indicators were used to explore if systems were functioning or non-functioning and served as proxy indicators for the strength of the health system in the aftermath of the EVD outbreaks. For example direct observation of an ambulance with a flat tyre and rusted exterior that was permanently parked at the entrance area to one of the health facilities provided empirical evidence of a non-functioning ambulatory service.

Clarifications from interviews sought to know if there were alternative vehicles used for ambulatory purposes. Combining direct observations with reported findings was used to draw conclusions about a functioning or non-functioning part of the health system. The ambulance example served to measure whether the health facility facilitated patient accessibility during emergencies. Other proxy indicators of health system strengthening included similar observations and cross- references to incinerators (waste management), water and sanitation systems (infection control) and laboratory equipment (diagnostic capacity). The volume of patients in wards and waiting areas were used as proxy indicators for the carrying capacity and intended function of the health unit again supplemented through the in-depth interviews and documented analysis. A checklist of resources was used in the questionnaires. These checklists were compared with the essential service provisions that appeared under each health facility level in the health sector strategic plan for 2005/2006 (Chapter one, Table 2). Observations were conducted up to saturation point in Bundibugyo and Kibaale.

Subjective observations noted during the interview process included the mood of the participant, the nature of the response and the type of interruptions recorded. Photographs were also taken throughout the data collection phase but for ethical reasons none captured patients or participants. Photographs were also subjected to the same data analysis process as the in-depth interviews using Strauss and Corbin's cyclic three-step guideline outlined below (Section 3.5.3). This combination of observation, document analysis and interviews contributed to answering research objective number one and four through triangulation by providing context for both research sites and indications to health system strengthening in the aftermath of the outbreaks.

3.4.3 Document Analysis

Documentary analysis is of particular use as an empirical source of data for qualitative case studies because it serves to ground the research in context (Stake, 1995; Yin, 1994). It is a means of evaluating documents in such a way that empirical knowledge is produced and understandings developed. In this study, documentary analysis provided an effective source of historical background to the political, social, and economical context two and seven years following the outbreaks respectively when events could no longer be directly observed.

According to Bowen (2009) document analysis is a systematic procedure for reviewing and evaluating printed and electronic documents to extract data that is examined and interpreted for meaning, understanding and empirical knowledge about the phenomenon under study. The advantage of using such material is that they provide background and context to the phenomenon described during the event. Documents also offer a cost effective method of data collection as the data has already been produced in document form. Another advantage is that documents contain text and images that are not influenced by the researcher as they have been produced independently of the study. Limitations of their use include accuracy, bias, and comprehensiveness of the data and therefore they cannot be used to supplement other sources of data (Bowen, 2009).

Unlike documents used in the scientific literature that have already been subjected to analysis, description and interpretation, documents used in a documentary analysis are sourced from the non-technical literature and are treated as raw data that need to be subjected to the same analytical procedure as data from interviews and observation (Bowen, 2009).

The documents used in this study were sourced, appraised, and synthesized as recommended by Bowen (2009). Hardcopy documents were sourced from libraries, organisations, institutions, and newspaper archives. Electronic documents were sourced on-line by using key words and phrases extracted from the main study objective used in the literature review (chapter two, section 2.2). These included relevant public records such as policy and protocol documents, reports from websites of international organisations including the WHO global alert website, CDC and humanitarian organization websites including MSF and Red Cross Uganda. Non-technical literature included newspaper archives from Uganda's two main daily newspapers, the *New Vision* and the *Observer* and the regional tabloid, *The East African*. Personal accounts such as blog posts and physical

evidence left at the study site such as artifacts, posters, and training materials were also considered documents and included in the study.

Using the following criteria documents were included as potential sources of empirical data to support the case studies if they:

- Provided background and historical context of the case study sites
- Pointed to additional and in-depth inquiry and identified situations or events that needed to be observed as valuable additions to knowledge
- Augmented existing data
- Provided a means of tracking change and development over time
- Verified findings or validated evidence from the interviews and observations.
- Provided global, national, or local perspectives through the language and style of narrative used.

Following selection, documents were scanned for relevant and non-relevant material (Corbin & Strauss, 2008; Strauss & Corbin, 1998). They were then read to identify relevant passages and text that allowed them to be categorised relevant to the study objectives. Finally, thematic analysis of the content was performed using the analysis technique outlined in section 3.5.3 below.

Cross checking across multiple document sources related to the two case studies assisted in verifying the descriptions outlined in policies and protocols versus the participant descriptions and observable realities on the ground (Table 3.3). Discrepancies in the chronological order of events described by participants during interviews such as the official announcement of outbreaks were clarified or validated using multiple document sources. Cross checking using documents from published sources also assisted to validate statistics on the numbers of deaths, confirmed and suspected cases, dates and place names. This helped to reduce some of the issues associated with recall bias. Document analysis also allowed the researcher an insight into how the events were captured and framed from local, national, and global perspectives. For example, the themes around the perceptions of a behaviour blame narrative and exceptionalisation emerged frequently from sources in the popular literature and were compared with local perceptions that arose from the data captured in the in-depth interviews (Table 3.3).

Table 3.3 Examples of Document Type and Function as Data Sources

Document Name	Type	Use
Health Sector Strategic Plan 2005/2006-2011/2011	Policy Document	To compare what was observed (empirical data) and described versus what was documented in the policy document
WHO Model of Infection Control (WHO, 2014g)	Protocol Document	To compare the resource capacity described and observed in the health units with what was required to implement the activities outlined in the WHO document.
New Vision Observer East Africa Blogs	Narratives on perspectives of EVD outbreaks in western Uganda in 2007 and 2012	Compared national, regional, and global narratives with local perspectives.

3.4.4 Field Notes

In the study field notes also contributed to the data by recording observations and supplementing data not captured by the participant interviews. Notes created by the researcher during fieldwork served as a reminder and a record of activities, events, behaviours, ideas and thoughts that were observed in the field but not recorded by other means such as audio recordings. These notes provided additional data that could be developed further and reflected upon at the end of each day.

Field notes also served to identify unanswered questions or concerns that emerged when scanning other sources of data and sometimes were used to clarify mistakes or misunderstandings captured in other parts of the field notes. During, following, and between interviews short notes were taken to record minor yet important details not audio recorded such as observations or participant perceptions captured outside of the recordings. Short notes were also captured on the mood of certain participants as being guarded, suspicious, defensive, open, or frustrated around the discussion of certain issues. This was important in terms of interpreting perceptions relayed during the interview process. For example during some interviews, guarded or defensive responses conveyed a sense of mistrust between the participant and the researcher. This suggests researcher effect as a limitation in the study where the researcher may have been perceived as someone with power who could expose the participant to criticism from higher levels.

Emotional responses, body language, and tone of the participant were also noted during the interview process. For example in the first few interviews the researcher realised that some of the questions were not appropriate for the context of a health centre and were frustrating

the participant as probably being out of context. A question about having an x-ray machine or fridge for storing medicines was one example. Despite piloting the questionnaire, the reason for this oversight was that the researcher originally had used the “levels of health service delivery” (Chapter one, Table 2) as a guide to the list of infrastructural resources that should have been in place at a Health Centre IV. However, it soon became evident during the early stages of data collection that the reality did not equate to the strategic plan describing district health services (Table 1. 2). This was noted and such questions were re-framed to “*what resources did you have available for diagnosis or storing medicines at the time of the outbreak*” for subsequent interviews where the researcher had to consider being more realistic and observant of the context. As the interviews progressed, the researcher became more familiar, relaxed and confident with the flow of the interviews and more sensitive to identify questions that were not relevant.

Field notes were sometimes used as evidence to provide meaning and an understanding of the context and phenomenon being studied. For example reading through and analysing field notes at the end of each day facilitated preliminary analysis by allowing the researcher to understand the social, cultural, and political context, and the participants role in the setting. It allowed the researcher to speculate on the meanings of what was observed from the perspectives of the participants and to identify emergent themes. Notes taken about the researcher's ideas, impressions, thoughts, and criticisms allowed for self-reflection. Self-reflection allowed the researcher to ask why she perceived certain events, activities, or thoughts as salient or deviant and how focusing attention on certain observations may have been influenced by her background knowledge and beliefs. This allowed the researcher to identify issues that may have previously seemed ‘less interesting’ in subsequent observations.

3.5 Data Analysis

3.5.1 Transcription

All 25 audio recordings were transcribed by the researcher, printed and grouped into bounded booklets for ease of access and use.

3.5.2 Approach to the Analysis

The approach used in analyzing the data was to adopt Strauss and Corbin (1990) cyclic three step grounded theory technique. This technique is one that is used to inductively derive knowledge from studying a phenomenon. According to Strauss and Corbin (1990) findings are discovered, developed and periodically verified through a systemic process of data collection and analysis of data pertaining to that phenomenon.

The rationale behind why the researcher chose a grounded theory technique for analysis arose out of a need to address the paucity of qualitative studies in the literature surrounding EVD outbreaks that went beyond a descriptive analysis. According to Holton (2010), grounded theory technique raises the analysis from the descriptive to the conceptual level. Adopting a grounded theory technique provided for conceptual construction of the participants experience to inductively arrive at theory. The researcher was attracted to the idea of trusting the data to arrive at a deeper understanding of local perspectives, not simply to deduct if the findings were similar or different to existing concepts.

According to Lincoln and Guba (1985), constructivists perceive reality as it is socially constructed and the role of the interpreter is to understand, reconstruct, analyse, and critique participants' views in a way that leads to meaningful findings or outcomes. By applying a grounded theory technique to reconstruct and analyse the data, this is what the researcher set out to achieve in meeting the study objectives.

3.5.2.1 Why Not a Grounded Theory Study?

There is much discussion in the literature surrounding the claim over a study as a grounded theory methodology. Following a review of the literature in grounded theory the researcher concluded that this study could not claim to be a grounded theory study, neither classical or a post- classical alternative such as constructivist grounded theory for the following reasons:

1. The researcher entered the study knowing there was a specific problem, from where the objectives emerged.
2. The researcher began the study by becoming familiar with the extant literature on Ebola as a global health phenomenon.

3. True theoretical sampling was not adopted. Sampling of participants, while not statistical, was not done in the ideal way outlined in a classical grounded theory study where following an initial stage of data collection a grounded theory study could take new directions, involving new study participants possibly at new study sites. Due to limited resources and the prolonged ethics procedure required in Uganda, this was not feasible as each application to the Presidents office is district specific.

Other researchers have managed to successfully defend making a shift towards a grounded theory study having started out on the traditional linear approach to research commencing with literature review, research question, and conceptual framework (Elliot & Higgins, 2012). Their arguments could support the researcher to claim grounded theory despite points 1 and 2 above. However, the main point of concern for the researcher was not applying a true theoretical sampling technique as outlined by Glaser and Strauss (1967). Attempting to defend this may be achievable but would inevitably result in what Glaser refers to as a “pick and mix” version of grounded theory where the resulting study no longer resembles grounded theory. The researcher entered the analysis phase retaining a constructivist theoretical perspective but adopted the grounded theory approach for analysing each case study, keeping in mind that the data itself would guide the theoretical perspective that best fitted the outcome. In conclusion, this is not a grounded theory study but adopts a technique for data analysis that has been used in grounded theory referred to as the cyclic three-step analysis technique (Strauss & Corbin, 1990).

3.5.3 The Cyclic Three Step Analysis Technique

The study followed Strauss and Colbin’s (1990), cyclic three-step analysis technique to initially make sense of a large volume of data using three coding processes referred to as open, axial and selective coding. These processes do not occur in isolation but overlap in a cyclical manner where the researcher switches focus between identifying codes within the data and by using the techniques of constant questioning and constant comparison to integrate these codes into more abstract categories and themes. The process is outlined below starting with a description of ‘open coding’.

Using an example taken from chapter five where ‘exceptionalisation’ emerged as the fourth theme from the analysis, excerpts from the data findings of both case studies are

used to describe the coding processes employed. A description of how the analysis process emerged by grouping similar concepts into categories that earned their way into this main theme and the use of constant comparison and constant questioning are described.

3.5.3.1 Open Coding

Following transcription of the data, the researcher repeatedly listened to each audio recording and read the associated narrative scripts to obtain a comprehensive understanding of what was going on. This is an important first step of the analysis procedure to become intimately familiar with the data, even before the formal coding process began.

The coding phase began by manually breaking down the data into fragments and identifying each fragment under a short descriptive sentence or conceptual code. The initial conceptual codes were either in-vivo codes (words or a short sentence taken directly from the data fragment) or sociological constructs (words or short sentence that would best describe the meaning of the sentence). This is the first step in the process referred to as 'open coding'. Coding was applied to all data sources including interviews, direct observation, and documents used in the study. The following example is taken from the data set of the 2nd in-depth interview from the Bundibugyo case study

“Like Unicef supplied us with these tents [] then WHO brought in the PPE’s, then Médecins Sans Frontières, they brought manpower, they brought doctors, nurses and the other supplies like IV fluids, supportive drugs [] they set up an isolation site in the recommended way, whereby we have got the suspected cases, the confirmed cases all those things were put in place by them.” (IDI, B2).

By asking the question “*What is this piece of data a study of?*” this fragment of data was initially coded as “*tents, PPE’s, manpower, drugs, isolation sites and things put in place by them*”. This is an example of in-vivo coding as the words were taken directly from the transcribed data. Alternatively, an in-vitro code or sociological construct conceptualizes the meaning of the same data fragment under a short descriptive sentence or term. Finally, “*EVD interventions*” was conceptualised to best describe this data segment.

The second step of the 'open coding' process involves grouping similar codes into categories. For example, by asking the question “*What category does this incident*

indicate?”. From here, the category of “*a humanitarian response*” was arrived at and similar codes were grouped under this category as the data contained many references to various types of interventions that came from international sources. As the analysis progressed, many codes were grouped under “*a humanitarian response*”. These included “EVD incentives”; “political will”; “identification with EVD”, “unmaking crises”, and “ethical issues”. Several categories emerged as the analysis technique was implemented.

Codes and categories from subsequent interviews were compared with those previously found as a frame of reference. For example when analysing subsequent interviews additional data segments were identified that fitted within the initial identified codes and categories while simultaneously new codes and categories emerged. This process of comparing data set to data set is central to the cyclic three-step analysis technique and is referred to as ‘constant comparison’. Initially all codes and concepts are provisional but the purpose of constant comparison is to validate if the data supports and continues to support the emergent categories by allowing similar concepts to be compared that are then grouped together into substantive and later theoretical categories. In addition, the process of constant comparison keeps the researcher close to the data hence reducing researcher bias.

3.5.3.2 Axial Coding

The second step in Strauss and Corbin’s (1990) cyclic three-step analysis technique is referred to as axial coding where data that was initially fragmented during open coding is reconstituted in new ways. Axial coding refers to new configurations and involves exploring linkages and variations between and within categories in terms of their context, how the participants responded to changing conditions and the consequences of their actions. The categories of ‘a humanitarian response’ and ‘aftermath of a crisis’ could be linked for example because they identified a contrast between the resources available during the EVD outbreaks with the aftermath period of the outbreaks. This emerged following the application of the technique of constant questioning by asking,

- What is going on here?
- Why has this occurred?
- In what context (background & conditions) does the phenomenon occur?
- What actions occurred, as a result of the phenomenon? (Glasser, 1992)

The following example demonstrates how the concept of *EVD Exceptionalisation* resulted from the process of axial coding by exploring linkages and variations between and within the categories of “*A humanitarian response*”, “*consequences of EVD exceptionalisation*” and “*aftermath of the crises*”.

Axial Coding around the category of *A Humanitarian Response*

Phenomenon: *What is going on here?*

A large number of resources and technical assistance were imported into Bundibugyo and Kibaale health units

Causal Conditions: *Why has this occurred?*

There has been an official announcement of an EVD outbreak and the Ugandan Ministry of Health supported by international development organisations are responding in terms of allocating resources to manage and control the outbreak.

Context: *In what context (background & conditions) does the phenomenon occur?*

The context is an EVD outbreak, perceived as a potential global health crisis that has emerged from within an impoverished community in western Uganda.

Action strategies: *What actions occurred, as a result of the phenomenon?*

The Ugandan MoH was supported by an immediate inflow of human, infrastructural, and financial resources from international organisations to co-ordinate management and control strategies to contain the outbreak. The event attracted political will and local, national, and international media attention.

Consequences: *What were the consequences, or outcomes of these actions?*

The health systems are supported to manage and control the outbreak. Deaths within the health facilities among staff and patients ceased and new cases reduced in the community. The outbreak was resolved within three months. Staff and surviving patients experienced both stigma and recognition. For the health workers and community this was perceived as an ‘exceptional’ response, when compared with other infectious disease outbreaks they witness in their line of duty, such as cholera.

As outlined axial coding involves exploring linkages and variations between and within categories. The category of ‘*A humanitarian response*’ is then compared with the category

of ‘*aftermath of the crises*’ in terms of variation between the two categories. ‘*Aftermath of the crises*’ refers to the contextual realities and lived experiences of the participants within the same health units two and seven years in the aftermath of the two EVD outbreaks. The same set of questions repeated in this category.

Phenomenon: *What is going on here?*

The health systems are overwhelmed with managing an endemic burden of disease, growing populations, an influx of refugees, a scarcity of resources to implement infection control, and several non-functioning systems to carry out their role.

Causal Conditions: *Why has this occurred?*

This situation has reverted back to a situation of non-preparedness as it was prior to the EVD outbreaks because it is perceived by the government and the international community that the crises in Bundibugyo and Kibaale districts has returned to ‘normal’.

Context: *In what context (background & conditions) does the phenomenon occur?*

This has occurred within a context of poverty, war, and conflict in neighbouring eastern DRC, a burden of endemic disease and lack of national or international support towards health system strengthening.

Action strategies: *What actions occurred, as a result of the phenomenon?*

There are talks of impending support for investment in the health facilities but no actions has been forthcoming up to the time of writing.

Consequences:

In the absence of health systems strengthening, the communities in Bundibugyo and Kibaale districts are vulnerable to future EVD outbreaks.

Following the process of axial coding for these two categories and the third category of “*Consequences of EVD Exceptionalisation*” (which underwent the same process of constant questioning) the theme of “*EVD Exceptionalisation*” emerged.

Continuing with the process of constant comparison, once categories were identified, three types of comparisons were made in the analysis to ensure that the theme continues to be supported and that the researcher maintains close contact with the data. First incidents were compared to other incidents to establish uniformity and the varying conditions

underlying them that generated concepts and hypotheses. Next concepts were compared to incidents to generate new theoretical properties. Finally, emergent concepts were compared to each other to establish best fit to integrate hypotheses into theory.

3.5.3.3 Incidents Compared to Other Incidents

The following incidents were similar in the sense that they refer to two life threatening but treatable conditions of patients presented at Bundibugyo General Hospital. The first incident was coded under “*EVD interventions*” and the second incident was coded under “*Overwhelmed resources for everyday realities*”. Later “*EVD interventions*” were grouped under the category of “*A Humanitarian Response*” because they related to actions that would not normally occur in response to everyday incidents in the health care setting in Bundibugyo. The second incident was later grouped under the category of “*Aftermath of the crises*” because it reflects the everyday situation experienced beyond EVD interventions. In the first incident, the participant is describing his experience as a patient receiving treatment for EVD and his gradual recovery in the isolation ward at Bundibugyo General Hospital in 2007.

they also put there some kamazi (IV fluids)... It was after those drugs [] we saw some kind of improvement because we could not walk, they wash you as a child, the whole body is very weak but when you started gaining, you started walking, you go in the toilet alone, walking [] you wake up in the morning, you brush [your teeth], [] they give you porridge, you take, then we saw there was some kind of improvement because appetite had gone [] and the number of people dying had reduced, [] there were no new patients coming in (IDI, B12)

In the second incident, a nurse describes her emotional response when she witnesses children dying from sickle cell anaemia because there is a lack of blood available in the hospital for transfusions. Anaemia (sickle cell anaemia) is an everyday health crisis in Bundibugyo hospital and has a prevalence of 5.5% in Kibaale district (UBOS, 2011).

I would like to see when blood is available, every time blood is there [] I always cry when children are dying because of anemia (IDI, B11)

3.5.3.4 Concepts Compared to Incidents

From the data, the theme of “EVD exceptionalisation” emerged from a number of categories. The concept that EVD was exceptional and therefore more important than endemic disease outbreaks more frequently experienced by the communities of Bundibugyo and Kibaale can be identified by comparing the following perception within the category of “*A humanitarian response*” to an incident reported from within the category of “*consequences of EVD exceptionalisation*”.

- *Uganda by then we were recognised, we have something even in the MS’s [medical supervisors] office, but in addition to that, we had certificates of recognition and already sending in messages to people, some of us are supposed to be going to Liberia, that is some recognition (IDI, K11).*
- *Of course the committees for cholera also could be there but not with a similar kind of seriousness. Because for this one (Ebola) you would find the chairperson, LC5, the RDC and the Chief Administration Officer are all there (IDI, B4)*

By comparing the concept with incident reported in the data, the main theme of “*EVD exceptionalisation*” emerges.

3.5.3.5 Comparing Concepts to Other Concepts

The third comparison made during the process of constant comparison was to compare concepts to each other to establish a best fit that can integrate hypothesis into theory. For example, there is a clear demarcation in each case study between the concept of “*A humanitarian response*” and “*Aftermath of the crisis*” . “*A humanitarian response*” refers to the context and conditions immediately following the announcement of EVD up to the announcement that the outbreak was officially over in both case studies. In the post-EVD period up to the time of data, collection the concept of “*Aftermath of the crises*” emerges in both case studies. As outlined above repeated incidents supporting the concepts of “*A humanitarian response*” and “*Aftermath of the crises*” establishes uniformity and the conditions under which the generated concepts and hypothesis occur. A hypothesis arising inductively from this analysis is that the burden of endemic disease and the lack of resources to manage them experienced by the communities in western Uganda are not perceived as sufficiently important to be defined as crises that warrant international support.

The process of constant comparison continued throughout the axial coding stage until saturation was reached. In other words, no new themes arose and further inquiry did not add anything new to the findings. \

3.5.3.6 Selective Coding

Selective coding involves linking and combining the abstract concepts that emerged during axial coding into the main themes and demonstrates how one overarching theme relates to all other themes and categories. *Disempowerment* emerged as the overarching theme from the study. The groups of codes and categories that emerged into five main themes are outlined in the findings chapters four and five under Data Presentations. The overarching theme of *Disempowerment* and how it relates to the five themes is explored in the discussion chapter. The next section describes how that data is presented.

3.6 Presenting the Findings and Discussion for the Research

3.6.1 Data Presentations

Following the data analysis process outlined above findings are presented in chapters four and five as open codes under categories and themes. Open codes are presented as groups of raw data segments extracted during the open coding process demonstrated in Figure 3.4.

Data Presentation 4.1.1.1
Theme 1: A Behaviour Blame Narrative
Category 1: Behaviour as a Determinant of EVD Emergence
Open Code 1: Hunting & Eating Bush Meat

- *Explaining these attacks, health experts believe human beings are largely to blame. Dr. Marian Nanyonjo, the disease prevention advisor, at the World Health Organisation in Kampala office says, “Ugandans are also known to love bush meat”*
(Observer, 2012; DA)
- *In Bundibugyo here there are still many people who are eating meat from wild animals [] someone finds himself with his dogs because the father and the grandfather used to hunt so he is having his three four dogs around, he goes to the bush, it is a habit*
(IDI, B4)
- *When you look at the sources of the infection, we still have poor eating habits, [] they think of going in the bush to hunt*
(IDI, B12)

- “Typically in the African setting that’s [contact with Ebola virus] been with hunting or eating, marketplaces where there I guess bush meat with monkey meat in it” (ABC news 31st July 2012, DA)
- “Some Ugandan ethnic groups living near the border of the DRC eat monkey meat” (Senior WHO official, Kampala, 2012)

Figure 3.4 Presentation of raw data segments grouped under open codes

These open codes were then grouped under categories as demonstrated in Figure 3.5.

Data Presentation 4.1.1		
Theme 1: A Behaviour Blame Narrative		
Category 1: Behaviour as a Determinant of EVD Emergence		
	(i) Hunting & eating bush meat	(Data Presentation 4.1.1.1)
	(ii) Congolese Refugees	(Data Presentation 4.1.1.2)

Fig. 3.5 Presentation of open codes under categories

Finally, categories are grouped under the main themes of the study demonstrated in figure 3.6.

Data Presentation 4.1	
Theme 1: A Behaviour Blame Narrative	
1.	Behavior as a determinant of EVD Emergence (Data Presentation 4.1.1)
2.	Beliefs as a determinant of poor health seeking behavior and delayed diagnosis (Data Presentation 4.1.2)
3.	Behaviour as a Determinant of EVD Transmission (Data Presentation 4.1.3)

Fig. 3.6 Presentation of categories under a main theme

3.6.2 The Medicoscapes Concept

In chapter six, the emergent themes and the linkages and concepts between them are discussed, guided by the *Medicoscapes Concept*. The *Medicoscapes Concept* is a framework that uses the metaphor of a ‘landscape’ to describe how multiple concepts of globalization in the field of health, their meanings and complex relationships can be brought together under one discussion (Figure 3.7).



Fig. 3.7 Metaphor of landscape used by the *Medioscapes Concept*

The Medioscapes concept is an extension of Appadurai's (1996) framework of 'scapes' (ethnoscapes, mediascapes, technoscapes, finanscapes and ideoscapes). These 'scapes' represent what Appadurai refers to as cultural flows that can be explored as the building blocks of 'imagined worlds' where individuals or groups can contest and subvert the 'official' mind. More specifically:

These are not objectively given relations that look the same from every angle of vision but, rather, that they are deeply perspectival constructs, inflected by the historical, linguistic, and political situatedness of different sorts of actors: nation-states, multinationals, diasporic communities, as well as subnational groupings and movements (whether religious, political, or economic), and even intimate face-to-face groups, such as villages, neighborhoods, and families (1996: 33).

Horbst and Wolfe (2014) extended Appadurai's framework through the concept of *Medioscapes* as an extension of existing globalisation theories that deal with health issues in a global context. Specifically the concept emerged to facilitate a broader umbrella to analyse and theoretically capture the ever more highly complex and heterogeneous

layers, processes and results of globalisation in the field of healthcare and international support. As outlined ‘landscape’ is employed as a metaphor to include a variety of dynamics including expressions of power relations, various types of elements, movements, pathways, agents and social and biological boundaries.

The Medicoscapes concept is defined by Horbst and Wolfe (2014) as:

Medicoscapes constitutes globally dispersed landscapes of individuals, national, transnational and international organisations and institutions as well as heterogeneous practices, artifacts and things which are connected to different policies, power relations and regimes of medical knowledge, treatments and healing. While concentrated in certain localities, medicoscapes connects locations, persons, and institutions via multiple and partially contradicting aims, practices, and policies (Horbst & Krause, 2004, p. 54-56).

Because of the multidisciplinary nature of this study, that considers the biological, cultural, social and political determinants of two EVD outbreaks and their contexts captured in global, national and local understandings, the Medicoscapes concept was identified as a suitable framework to discuss the findings. It was also useful as a tool to link the five main themes under the overarching theme of *Disempowerment* that emerged from the analysis.

3.7 Assessing Rigour

According to Miles and Huberman (1994) good qualitative research contributes to science through the use of a consistent chain of reasoning, by using multiple sources of converging evidence to support an explanation and ruling out conflicting hypothesis with convincing arguments and solid data. In this section, the researcher outlines how the study methodology was conducted to ensure ‘good research’ in terms of the reliability and validity of the data and the reduction of researcher bias in arriving at the findings. The researcher uses *reliability* and *validity* as a means of assessing the ‘truth’ of the data.

3.7.1 Credibility

Credibility questions whether the right type of data was actually collected to meet the objective of the study and to what extent the researcher's findings are an accurate representation of the participants understanding.

The efforts made by the researcher to achieve this were as follows:

- (i) Theoretical sampling ensured that the sources of data chosen were relevant to meeting the study objectives. For example, an inclusion criterion for participants within each case study was that they had experienced one of the EVD outbreaks in the capacity of an employee within the health system, a patient or family member of a patient from within both communities.
- (ii) Adopting a grounded theory technique of analysis ensured that the analysis was grounded in the data. For example during open coding, the researcher used *in-vivo* coding (i.e. the participants own words) wherever possible as a means of describing a section of data. Constant comparison was used within this technique to compare each interview for analysis to the previous interview and to previous emerging concepts thereby approaching the data analysis as a whole unit. Constant questioning kept the researcher close to the data and minimized researcher effect.
- (iii) In this study, data *triangulation* was used to support the validity of the data by employing multiple data sources (in-depth interviews, observation and documents) where the data could corroborate. In relation to in-depth interviews, respondents were required to answer honestly. However, the possibility of social desirability cannot be ruled out as the majority of participants were public servants working within the MoH and some may have feared to criticise the government, and may have been conservative in offering their true opinions. Others may have felt that they needed to justify that they were performing their duties adequately. For example, it was observed that some participants' relayed events related to surveillance and response interventions in what seemed to the researcher as a textbook or learned version of how things should be done. Some participants may have felt that this was an opportunity to impress upon the researcher that they were experts in the field, perceiving the researcher as a person of power. These realities became clearer during subsequent interviews and through other data sources that contradicted some facts. The researcher conducted all of the interviews within the settings where the outbreak occurred so she could directly observe the context. Documents such as WHO reports and

media archives were used for cross reference to validate dates and the chronological order of events and to help reduce recall bias. This was useful, particularly for the Bundibugyo case study where there was a seven-year time lapse since the outbreak and the data collection period. A two-year gap existed between the Kibaale outbreak and data collection.

3.7.2 Transferability

Transferability poses the question ‘would similar findings be found if the study was repeated’ in another context. As the study took place within its natural setting within the social world, it would not be possible for the findings to be exact. For example, delays in the announcement of Ebola, as in the Bundibugyo case, might not be repeated in a world more sensitised to EVD under improved global health regulations and surveillance strategies or in different political contexts. The response may be more organised with increased capacity and confidence gained by the participants in the first outbreak or outcomes may be worse than before if the participants or external actors were over-confident that they could resolve the issue (the West Africa outbreak for example demonstrated an unexpected and unprecedented outcome of an EVD outbreak). A reader of this study might ask would the findings of this study be similar if the study was repeated in Sierra Leone or Guinea.

Interpretive sociologists recognise that meanings arise through interaction and are not standardised across social and cultural groups. Accounts and assumptions are investigated and analysed as research data, rather than representations of phenomenon of interest. Although interpretive analysis of the data generates only theoretical propositions, and case studies are not generalisable, they are however useful in providing important insights and a broader understanding applicable beyond the immediate surroundings of the two studies. Using two case studies helped to support the robustness of the findings.

3.7.3 Dependability

This refers to the extent to which the methodology used in this study would produce the same findings if carried out by another researcher. In constructivist studies this is however

questionable as the researcher is part of the cognitive analysis of the social world and cannot be completely value free.

One of the functions of constant comparison is to reduce researcher bias. The researcher remained conscious of this fact, kept close to the data and strove to avoid allowing personal values and perspectives to influence how the findings were interpreted. Contradictory or deviant cases were accounted for in the analysis, to ensure the researcher was not biased in supporting one view. *Triangulation* discussed above also helps to counter threats of researcher bias by using diverse data sources to validate findings and give a more complete picture. The use of document analysis for example did not have any potentially distorting effect of the researcher in the field. In addition, a strong familiarity with the context was ensured to avoid over simplicity or in arriving at narrow views in understanding a 'local' social or organisational culture for example. Efforts made here by the researcher were to allow the process by which findings were arrived at, to be auditable. In other words being explicit about the methodology, being articulate about the lines of enquiry and by offering a reflexive account of her position within the study.

A similar study using a phenomenological approach that covered the Kibaale case study undertaken approximately one year before this study was identified during this study (Matua, 2014). The study focused specifically on the human experience but similar findings were identified including internal and external coping strategies, fear, stigma, ostracism, and adaptation. This offers some support that the findings are dependable.

3.7.4 Confirmability

Confirmability refers to objectivity and control of researcher bias. The position of the researcher in the study was made explicit from the onset. Limitations of this study in developing a true 'southern theory' are that the researcher originates from the global north. Therefore, only the participant views are 'southern', and these have been constructed through the eyes of the 'northern' researcher. The researcher has resided in Uganda and Rwanda within the contexts of two public institutions for over six years for the duration in which the study was conducted, but, while she may have a good understanding, cannot declare that she has a *full* understanding of the context. The researcher was conscious to bracket her experience and ongoing position in the field during the analysis to reduce bias.

3.8 Chapter Summary

Chapter three has attempted to give a comprehensive account of the research methodology, including theoretical assumptions, study design, process of data collection including access, ethics protocol followed and the methods employed. Strauss and Corbin's (1990) cyclic three-step guideline used to analyse the data is described using the theme of *Exceptionalisation* as an example. How the findings from the analysis are presented and discussed is also described. Finally, the researcher outlines how the study methodology was conducted in terms of reliability and validity of the data findings.

Chapter 4: Findings Part 1

4.1 Introduction

Chapter four and five present the study findings generated from the data. As outlined in the methodology chapter Strauss and Corbin's cyclic three-step technique was employed to analyse the data. The data was fragmented into coded segments and through the process of constant questioning and constant comparison; groups and categories were generated and formulated into themes. Five main themes emerged from the analysis. In this chapter, findings are presented under three of these themes: A Behaviour Blame Narrative, Social Realities, and Structures of Disempowerment.

The three themes presented in this chapter emerged from seven categories and 24 groups generated from the open coding process. Table 4.1 summarises the themes and categories and their associated data presentations. The data presentations are comprised of data segments that include verbatim quotes from interviews, documents, or photographs that captured observations. Each data segment indicates the data source as in-depth interview (IDI), document analysis (DA) or direct observation (DO) to allow triangulation to be evidenced. These units of data provide empirical evidence that formulated the groups and categories under each theme. The three main themes in this chapter are presented in a way that captures contrasting perspectives of events and understandings between a dominant 'global' narrative portrayed in theme one with narratives that are subordinated in theme two and three captured by local voices.

The findings in this chapter contribute towards the first, second and third study objectives that capture contextual realities, local understandings and lived experiences of the two outbreaks and their external interventions. The data presented comprises both descriptive accounts of incidents and lived experiences and individual perceptions around those events. Emergent themes and categories are supported with reference to the literature.

Table 4.1 Summary of themes and categories generated from the analysis

THEME 1: A Behaviour Blame Narrative	Data Presentation 4.1
1. Behaviour as a Determinant of EVD Emergence	Data Presentation 4.1.1
(i) Hunting & eating bush meat	Data Presentation 4.1.1.1
(ii) Congolese refugees	Data Presentation 4.1.1.2
2. Beliefs as a Determinant for Poor Health Seeking Behaviour and Delayed Diagnosis	Data Presentation 4.1.2
(i) Witchcraft and spiritual forces	Data Presentation 4.1.2.1
(ii) Poisoning	Data Presentation 4.1.2.2
(iii) God and spiritual forces	Data Presentation 4.1.2.3
3. Behaviour as a Determinant of EVD Transmission	Data Presentation 4.1.3
(i) Burial practices	Data Presentation 4.1.3.1
THEME 2: Structural Determinants of Delayed Diagnosis and Nosocomial Transmission	Data Presentation 4.2
1. Institutional Hierarchies	Data Presentation 4.2.1
(i) Marginalised communities	Data Presentation 4.2.1.1
(ii) Institutional hierarchies	Data Presentation 4.2.1.2
(iii) Political determinants of delayed response	Data Presentation 4.2.1.3
(iv) Disempowered health workers	Data Presentation 4.2.1.4
(v) Experiences of despair and helplessness	Data Presentation 4.2.1.5
2. Weak Health System	Data Presentation 4.2.2
(i) Non-preparedness	Data Presentation 4.2.2.1
(ii) Overburdened health system	Data Presentation 4.2.2.2
(iii) Poor surveillance and diagnostic capacity	Data Presentation 4.2.2.3
(iv) Lack of resources to implement infection control	Data Presentation 4.2.2.4
(v) Lack of support to health workers	Data Presentation 4.2.2.5
(vi) Endemic burden of disease	Data Presentation 4.2.2.6
THEME 3: Social Realities	Data Presentation 4.3
1. Poverty	Data Presentation 4.3.1
(i) Population growth & food insecurity	Data Presentation 4.3.1.1
(ii) Living conditions	Data Presentation 4.3.1.2
(i) Limited income sources	Data Presentation 4.3.1.3
(ii) Barriers to accessing healthcare	Data Presentation 4.3.1.4
2. War	Data Presentation 4.3.2
(i) Civilian attacks	Data Presentation 4.3.2.1
(ii) Human displacement	Data Presentation 4.3.2.2
(iii) Living conditions in refugee camps & settlements	Data Presentation 4.3.2.3

4.2 A Behaviour Blame Narrative

Data Presentation 4.1

Theme 1: A Behaviour Blame Narrative

Behaviour as a Determinant of EVD Emergence (Data Presentation 4.1.1)

Beliefs as a Determinant for Poor Health Seeking Behaviour & Delayed Diagnosis
(Data Presentation 4.1.2)

Behaviour as a Determinant of Transmission (Data Presentation 4.1.3)

From the analysis, the theme of ‘a behaviour blame narrative’ emerged which assigned blame as a cultural determinant of EVD emergence, delayed diagnosis, and transmission surrounding the 2007 and 2012 outbreaks in western Uganda. The ‘behaviour blame narrative’ is an explanatory model that suggests that individuals or groups are responsible for unfavourable health outcomes as a result of engaging in risky behaviour or by neglecting to take responsibility for their health and thereby predisposing themselves to conditions that negatively impact on their welfare. The ‘behaviour blame narrative’ has been previously identified in relation to infectious disease emergence (Farmer, 2005; Petros, 2006; Eichelberger, 2007; Dry & Leach, 2010; Jones, 2013).

4.2.1 Behaviour as a Determinant of EVD Emergence

Data Presentation 4.1.1

Theme 1: A Behaviour Blame Narrative

Category 1: Behaviour as a Determinant of EVD emergence

- | | | |
|-------|----------------------------|-----------------------------|
| (iii) | Hunting & eating bush meat | (Data Presentation 4.1.1.1) |
| (iv) | Congolese Refugees | (Data Presentation 4.1.1.2) |
-

In the study, two assumptions relating to behaviour as a cultural determinant of EVD emergence were identified from the analysis. These behaviours included hunting and eating bush meat and the presence of Congolese refugees.

4.2.1.1 Hunting and eating bush meat

Data Presentation 4.1.1.1
Theme 1: A Behaviour Blame Narrative
Category 1: Behaviour as a Determinant of EVD Emergence
Open Code 1: Hunting and eating bush meat

- *Explaining these attacks, health experts believe human beings are largely to blame. Dr. Marian Nanyonjo, the disease prevention advisor, at the World Health Organisation in Kampala office says, “Ugandans are also known to love bush meat”*
(Observer, 2012; DA)
 - *In Bundibugyo here there are still many people who are eating meat from wild animals [] someone finds himself with his dogs because the father and the grandfather used to hunt so he is having his three four dogs around, he goes to the bush, it is a habit* (IDI, B4)
 - *When you look at the sources of the infection, we still have poor eating habits, [] they think of going in the bush to hunt* (IDI, B12)
 - *Typically in the African setting that’s [contact with Ebola virus] been with hunting or eating, marketplaces where there I guess bush meat with monkey meat in it”* (Health Expert, ABC news 31st July 2012, DA)
 - *“Some Ugandan ethnic groups living near the border of the DRC eat monkey meat”* (Senior WHO official, Kampala, 2012)
-

Presentation 4.1.1.1 conveys understandings from media reports and some interviews that hunting and the consumption of bush meat is a cultural determinant of EVD emergence. An understanding that hunting and consumption of bush meat was responsible for EVD emergence and transmission was identified in both case studies but predominantly from sources external to the outbreaks.

Evidence to support these narratives that bush meat consumption was linked to the emergence of EVD have never been scientifically linked in any of the five outbreaks that occurred in Uganda between 2000 and 2012 (Mbonye *et al.*, 2012). A definitive reservoir host for EVD transmission has not been identified to date, therefore natural infection cannot be ruled out. A recent study by Paige *et al.* (2015) expands the ‘bush meat paradigm’ by demonstrating that infection with EVD in western Uganda occurs in areas where bush meat hunting does not commonly occur. These areas include mixed landscapes shared by people and wildlife such as farms and forest fragments where human-wildlife contact is indirect and incidental. According to Okware *et al.* (2015) the index case in the Kibaale outbreak was opening up forestland with her husband when she fell sick. This shares similarities with the single case study reported in Luwero, Central Uganda in 2011, where there was no evidence of direct animal contact (Shoemaker *et al.*, 2012). Living in an environment where the virus exists presents in itself a risk factor for exposure without

necessarily being preceded by consumption of or direct contact with an infected animal. As outlined in section 2.4.3 people living in Central African forests have previously been identified with antibodies to indicate past infection not necessarily linked to consuming bush meat (Leroy *et al.*, 2000; Gondalez *et al.*, 2000; Busico *et al.*, 1999; Bequart *et al.*, 2010). Evidence that zoonotic transmission between pigs and humans related to occupational contact was also confirmed in the USA (WHO, 2009). This supports the argument that humans can be exposed to natural infection of Ebola virus that is not always attributed to consuming an infected carcass.

4.2.1.2 Congolese refugees

Continuous influxes of Congolese refugees into western Uganda are frequently associated as responsible for the emergence or imminent threat of EVD in Uganda.

Data Presentation 4.1.1.2
Theme 1: A Behaviour Blame Narrative
Category 1: Behaviour as a determinant of EVD emergence
Open Code 2: Congolese Refugees

- *I have severely noticed this, whenever Congolese refugees are in Uganda, believe me there will be a case of Ebola in any bordering areas of Uganda and Congo, western part of Uganda or northern. Seems the Ebola disease is originated from Congo, reason, the Congolese are greedy people, they eat whatever called meat, gorillas, all types of primates including dogs, they are the reason of Ebola in the country (Kyamanywa A., The Monitor, 2012, DA).*
 - *The latest outbreak in Uganda has been linked to an influx of an estimated 20,000 refugees from the eastern Democratic Republic of Congo fleeing fighting in North Kivu province. But a direct cause-and-effect link between the entry of refugees and the outbreak of the disease has not been established (Barigaba J. and Mungai C., The East African, 2012, DA)*
-

The findings demonstrate how ‘Congolese’ refugees are assumed a determinant of EVD emergence in Uganda. The first excerpt refers to a comment that appeared in response to an article in one of Uganda’s daily newspapers, the *Daily Monitor*, referring to the Kibaale outbreak in 2012. The commentator blames the behaviour of Congolese refugees as the source of EVD emergence in Uganda. This perspective identifies with the second anthropological perspective to fault an adversary as a meaning for assigning blame for misfortune outlined by Douglas (1992). During the EVD outbreak in Gulu, northern Uganda between 2000 and 2001 military personnel returning from the DRC, were blamed for the EVD outbreak (Hewlett, 2001).

4.2.2 Beliefs as a Determinant for Poor Health Seeking Behavior and Delayed Diagnosis

‘Behaviour blame narratives’ frequently refer to poor health ‘choices’ such as delaying seeking healthcare intervention or seeking informal sources of health care such as private drug dispensers or traditional healers.

“also this community has a lot of traditional healers and a big portion of our community still believes in the treatment of a traditional healer whereby before a patient is brought to a health facility, in most cases he is first treated by a traditional healer, using some herbs in which case sometimes don’t work properly” (IDI, B4)

Data Presentation 4.1.2		
Theme 1: A Behaviour Blame Narrative		
Category 2: Beliefs as a determinant for poor health seeking behaviour & delayed diagnosis		
(i)	Witchcraft	(Data Presentation 4.1.2.1)
(ii)	Poisoning	(Data Presentation 4.1.2.2)
(iii)	God and spiritual forces	(Data Presentation 4.1.2.3)

Blame is assigned to the beliefs of those individuals or communities who assign poison, witchcraft, or higher forces to health outcomes and hence contribute to a delayed diagnosis and response to EVD outbreaks. This is because it is perceived that those who believe in supernatural causes for EVD emergence are more likely to seek supernatural solutions (Matua, 2014). Seeking health services from traditional healers is perceived as a rejection of modern biomedicine and therefore a determinant of delayed diagnosis as cases are not initially admitted to formal health facilities for investigation. This resonates with a ‘behaviour blame narrative’, implying that poor timing to access health services is based on bad habits rather than other social factors such as poverty. In the study none of the frontline health workers who treated patients at the centre of the outbreak assigned poor health seeking behaviours as a determinant for delayed diagnosis. The ‘behaviour blame narrative’ may reflect an educational or socio-economic dichotomy between the community and those who have access to public education and ‘know best’.

4.2.2.1 Witchcraft

Data Presentation 4.1.2.1		
Theme 1: A Behaviour Blame Narrative		
Category 2: Beliefs as a determinant for poor health seeking behavior & delayed diagnosis		

Open Code 1: Witchcraft

- *There were many stories that so many people were dying on such a place and so people were mainly attributing it to witchcraft so these people were not coming to hospital (IDI, K1)*
 - *People, they started thinking maybe they have been charmed what? (IDI, K2)*
 - *The affected families initially thought it was either witchcraft or evil spirits. As a result they took the first patients to Owobusubizi Bizaka's shrine for prayers. Bisaka is the leader of a religious sect called Faith of Unity. Two patients died at that shrine. (Vision Team/New Vision, 2012, DA)*
 - *But she still wasn't convinced that her family had died of the virus. Why had some perished and others been spared, she demanded to know. Why had she tested negative? "We explained it to her thoroughly, but she doesn't accept it," Tusubira said, as we walked back from the cemetery to the car. "Even now she suspects that it was witchcraft." (Smithsonian, 2012, DA)*
-

The excerpts outlined above convey blame towards the communities for delayed intervention based on their beliefs in witchcraft versus seeking conventional health services. The case studies revealed how multiple members within families in the community were reported to have died suddenly from a 'strange disease'. Stories of poisonings between rival ethnic groups and witchcraft were commonly offered as a cultural explanation for sudden deaths, portrayed by the media as a norm of understanding within these communities. This concept of poisoning as a plausible cause of death, particularly sudden or unexplained death among the communities was also a commonly cited explanation for delayed diagnosis in both case studies. These views were mostly reported during and following the intervention periods captured by media sources and conveyed by some health workers and district officials.

From an epidemiological perspective, these concepts are portrayed as cultural determinants of delayed diagnosis and amplification of virus transmission during outbreaks, as they result in oversight of cases being brought to the attention of official health authorities.

4.2.2.2 Poisoning

Data Presentation 4.1.2.2

Theme 1: A Behaviour Blame Narrative

Category 2: Beliefs as a determinant for poor health seeking behaviour and delayed diagnosis

Open Code 2: Poisoning

- *They were thinking of poisoning that's why so many people died they were thinking of also being poisoned [] because we were thinking that maybe people are given poison [] some people were thinking certain tribe is trying to give poison to other people (IDI, B2)*
- *others were talking of poisoning as I have told you, maybe they had poisoned the food, maybe they had poisoned the cooking oil which they use so there were misconceptions about it (IDI, B8)*

- *Maybe people have poisoned this cassava flour or this cooking oil that's why people are dying in Kikyo, intestines are rotting there, what (IDI, B11)*
 - *Then maybe, for them they were thinking of maybe food poison....(IDI, K4)*
-

Participants from both case studies reported that the community believed that food sources had been poisoned by an enemy or an adversary (*certain tribe is trying to give poison to other people*). This perception emerged from reports that the disease resulted in gastro-intestinal symptoms preceding the death of some of the victims.

4.2.2.3 God and spiritual forces

Data Presentation 4.1.2.3
Theme 1: A Behaviour Blame Narrative
Category 2: Beliefs as a determinant for poor health seeking behavior & delayed diagnosis
Open Code 3: God and spiritual forces

- *There is a system of praying that maybe some people are having ghosts and what what (IDI, B2)*
 - *Some people delayed seeking treatment because they believed that evil spirits had sickened them, according to reports from the district health authorities (CNN, August 1, 2012, DA)*
 - *What I can say, this outbreak, you know it is Gods plan, sometimes god wants to punish people, to punish regions (IDI, B12)*
-

Some participants reported that the affected communities believed they had been cursed [*having ghosts*] so they sought prayer from healers who they believed could intervene. Others believed God had punished their communities [*sometimes God wants to punish people, to punish regions*].

4.2.3 Behaviour as a Determinant for EVD Transmission

Data Presentation 4.1.3
Theme 1: A Behaviour Blame Narrative
Category 3: Behaviour as a determinant for EVD transmission
Burial Practices (Data Presentation 4.1.3.1)

4.2.3.1 Burial practices

Data Presentation 4.1.3.1
Theme 1: A Behaviour Blame Narrative

Category 3: Behaviour as a determinant of transmission
Open Code 1: Burial Practices

- *You see culturally here you have to give last respect just by either being like this on the dead body [demonstrates placing hands] (IDI, B2).*
 - *Because when we leave them there, they will steal in the grave, they will wish to perform, you know we have different cultures, others believe when a person dies you must first bathe the person before burial (IDI, K3).*
 - Many wept and caressed the corpse following Ugandan custom (Hammer J., Smithsonian Magazine, 2012; DA)
-

Procedures associated with burial practices such as contact with infected body fluids or skin have been epidemiologically identified as a mode of EVD transmission where the deceased was infected with Ebola virus (Bausch *et al.*, 2007, Francesconi *et al.*, 2003). A person may become infected with the virus when preparing a body for burial and the persons attending the burial service may directly contact the body through a kiss or a touch as a gesture for giving last respect to the deceased. Burial practices were also mentioned in terms of culture by external sources and by those trained to work in the burial teams during both outbreaks.

4.3 Structural Determinants of Delayed Diagnosis

The second main theme to emerge from the analysis referred to a number of structural determinants that offer alternative yet plausible explanations for the delayed diagnosis of the EVD outbreaks in 2007 and 2012. These emerge under the theme of ‘structural determinants of delayed diagnosis’ and refer to limitations that comprise the contextual realities and experiences for the communities and health workers in western Uganda.

Data Presentation 4.2

Theme 2: Structural Determinants of Delayed Diagnosis

1. Response hierarchies (Data Presentation 4.2.1)
 2. Weak Health Systems (Data Presentation 4.2.2)
-

4.3.1 Response Hierarchies

The category referred to as ‘response hierarchies’ refers to a hierarchal system from the village to the government level that demonstrates the power dynamics that determine how responses towards infectious disease epidemics are perceived and controlled.

Data Presentation 4.2.1		
Theme 2: Structural Determinants of Delayed Diagnosis		
Category 1: Response Hierarchies		
(i)	Marginalised Communities	(Data Presentation 4.2.1.1)
(ii)	Institutional Hierarchies	(Data Presentation 4.2.1.2)
(iii)	Political determinants of delayed diagnosis	(Data Presentation 4.2.1.3)
(iv)	Disempowered health workers	(Data Presentation 4.2.1.3)
(v)	Experiences of despair and helplessness	(Data Presentation 4.2.1.4)

4.3.1.1 Marginalised communities

The global narrative outlined above frequently frames rural isolated communities as ignorant and backward conveying behaviours and beliefs that accelerate EVD emergence and amplification. However, an alternative explanation to delays in diagnosis underlying multiple deaths within these communities was identified under a category that demonstrated how these communities were frequently marginalised and ignored despite a bottom up structure of health service delivery starting at the village level as outlined in section 1.1.2.

Data Presentation 4.2.1.1		
Theme 2: Structural Determinants of Delayed Diagnosis		
Category 1: Response Hierarchies		
Open Code 1: Marginalised Communities		

- *So when we ever reported to the district, there was some delays in the district, they said it is intestinal worms disturbing these people [] so there was a delay of arresting the suspicion. So now, one of the health workers also got affected. (IDI, B1)*
- *Like there was a home, just one home, 14 of them came from one home [] one house and seven of them died [] Because the other time also the district had the other thing in mind because of this tribal [ethnic conflicts], there could be some poisoning what what so it was not taken so seriously as such. (IDI, B2)*



*Family receive basic care package following the Kibaale 2012 EVD outbreak.
Source: Okware, 2015 (DA, P1)*

- *So far 3 people have died and then of course the problem we had at that time, there were shortages of transport, moving and things like that, you know movement is difficult and then you are occupied with many other things there, the health assistant has not gone, the lab person has not reached taking the specimens, the people have not gone to the hospital, you know that type of thing (IDI, K7)*
- *There were stories, there were many stories that so many people were dying on such a place and so people were mainly, the communities sort of isolated them [] it was from the staff that we discovered it was Ebola, because it was her sample that was examined, first proved that it was Ebola (IDI, K1)*
- *When our staff died, that is when we had to know that it is Ebola [] it is when the Ministries came down then is when we know that it is Ebola (IDI, K5)*



*Community who experienced EVD outbreak in Bundibugyo.
Source: WHO Photostory 22nd February 2008 (DA, P2)*

The first excerpt refers to how health care workers in Bundibugyo reported multiple deaths among impoverished communities but the authorities dismissed the reports as ‘intestinal worms’. The second excerpt refers to a report that 14 people in one household died but it

was not taken seriously from the district office dismissing it as tribal conflict. The third excerpt captures a disorganised response and a languid attitude at the district level towards investigating deaths reported from communities. Several excerpts from both case studies convey how it was the death of health workers that triggered any serious interest from the MoH. In Bundibugyo, there was a delay of almost five months following initial reports of multiple deaths in certain communities. In the Kibaale outbreak, a delay of almost one month occurred between when the death of a senior health worker and her child triggered the initial response. None of the previous reports on multiple deaths among marginalised groups warranted a public health intervention. This was also the case reported in Gulu, northern Uganda in 2000 when initial investigations followed the death of a health worker and 2 student nurses in October at the missionary hospital despite earlier presumptive cases reported in the community since August 2000 (Okware, 2002).

Data Presentation 4.2.1.1 lies in contrast to data presentations 4.1.1 and 4.1.2 above under the theme of a ‘behavior blame narrative’ where ‘health experts’ blamed the communities for delayed interventions because of their cultural behaviours and beliefs. An imbalance emerges from the findings between the narratives captured by media and scientific reports versus the realities on the ground. For the social marginalised groups comprising isolated rural communities, their voices remain absent from the dominant narrative. These findings also demonstrate weakness in the functioning of the national health service delivery structure, which posits that health services begin at the village level (Chapter 1, Table 1.2).

4.3.1.2 Institutional hierarchies

The findings in this study reveal that the majority of the health workers were also low in the hierarchy of the health system and therefore had little power at the decision-making level to inform change or influence intervention at the time of the EVD outbreaks.

Data Presentation 4.2.1.2
Theme 2: Structural Determinants of Delayed Diagnosis
Category 1: Response Hierarchies
Open Code 2: Institutional Hierarchies

- *health centre II's, health centre III's it is just push system [] these other lower units government is just pushing so you find that they have supplied few boxes of gloves[] and those things are just consumables, they are being consumed within the shortest time, like these eh gowns and what what (referring to the protective clothing) those one we don't get things like aprons, things like masks, like goggles, those ones are maybe at health centre IV and the hospital (IDI, B2)*

- *but sometimes when there is a training which is normally through workshops, there are particular people who are selected to attend the workshops and normally when they are through with the workshops they come, they don't pass the information, the knowledge to the lower people so we still have very many people who lack knowledge (IDI, B5)*
 - *You know the funny thing is that for us in the lab mostly we don't make decisions, we give our report and they the doctors who conclude? So whether there were (assumption?) or not there was nothing I could propose (IDI, B6)*
 - *for when we had the outbreak, actually it was WHO now to budget for us, not me to get involved in the budgeting, actually they are the ones who budget and said we shall give you this and this and this so there is no alternative of saying this is not enough for this and this is not enough for this.... (IDI, K2)*
 - *like here our hands are tied up, the medical superintendent will say "any requisition must go to CAO", so the time you spend to reach from here to go to the CAO, and a lot of things have taken place already (IDI, K3)*
-

4.3.1.3 Political determinants of delayed response

Control over the decision to make an official announcement of EVD in 2007 was controlled at the level of central government.

Data Presentation 4.2.1.3

Theme 2: Structural Determinants of Delayed Diagnosis

Category 1: Response Hierarchies

Open Code 3: Political determinants of delayed response

- *by that time because we had the Queen of England was CHOGM so they never revealed the results when the CHOGM was still in until the 29th of November it was when they released the result that it is Ebola (IDI, B2)*
 - *in politics you are not supposed to say things are not ok, there are a lot of control so things are always like this and maybe partly that one affects why we don't benefit. [] we should come up and say things are not ok, this and this is missing, following this outbreak this and this happened, maybe then people would be, "Eh why don't we go there and give them a hand (IDI, K11)*
 - *then that could mean that because I remember rumour had it that tests had been made and diagnosis made and government discouraged the disclosing, the what?the information for fear that it was very sensitive information for the fear that CHOGM could not take place. But the very serious part of this disease was August 2007 (IDI, B4)*
 - *there was some rumour and suspicion that the coming of the Queen to Uganda prevented the declaration of Ebola. But it seems the Ministry already knew and actually maybe to try and confirm such political statements was that I took a sample to Kampala, to Entebbe [] so I went up to Entebbe with the sample, but when I reached to the office the way I was received there was unique. "Ah stop there, put your sample there, go and wash hands". Then I say what is wrong with these people? I have always being bringing samples here but they don't treat me like a stranger but this time is different [] those people in the Ministry already knew by the time I was there for them they knew but on the ground, nobody knew [] It was declared the following day after the Conference, after the Queen had left Uganda, that's when they declared (IDI, B6)*
-

A political determinant underlying delayed diagnosis in the Bundibugyo case study emerged from the analysis following several references made towards the Commonwealth Heads of State General Meeting (CHOGM) event hosted in Uganda in 2007. This was perceived as a factor that contributed towards a delay to announce the EVD outbreak only after delegates had departed from Uganda on the 29th November 2007. Despite ratification of the revised IHR in 2007, this event shares similarities to the delay or failure to announce the SARS outbreak in China in 2002.

4.3.1.4 Disempowerment of health workers

The term ‘disempowerment’ refers to a loss of agency to control or influence decision making processes. Several examples of disempowerment experienced by the health workers were identified in the study.

Data Presentation 4.2.1.4

Theme 2: Structural Determinants of Delayed Diagnosis

Category 1: Response Hierarchies

Open Code 4: Disempowerment of health workers

- *the type of employment I have it is actually tying me here, the government can offer employment whereby you are recruited in this district, you cannot say now I want to go to Kampala district or Mbarara. If you want to go there you have first to resign this job and reapply there and get a job there (IDI, B6)*
 - *there is no running water in the mortuary and this is an area according to the training I have undergone which is supposed to be the most clean part..... you must look for water from other sources, you take it there and you look for some people and of which they also need money, I don't have the money to pay them.....so I have ever made that complaint since 2009, writing the complaints of the mortuary and nobody has ever taken it into consideration, mortuary has no power, no running water... (IDI, K3).*
 - *I work in the hospital but I am outside the quarters, I am called from outside to come and work, so even the renovation of the quarters has never happened, has never taken place. Then the houses are not good for living [] others are living in one room with the whole family, yeah staff quarters is not enough, staff housing is not the best (IDI, B10)*
 - *I told him “doctor I am suspecting haemorrhagic fever”, for him he thought it was not, he didn't take it serious. Then after a few days, I went to him again and he told me it is likely to be intestinal worms. So people started thinking it was intestinal worms from the word of the doctor but me I was suspicious because of some of the symptoms I was taught those people presented with (IDI, B5)*
-

In the first excerpt a health worker was asked why he remains in the system despite the challenges, lack of support and geographical isolation. His response revealed the larger

structural forces underlying his lack of agency experienced in the context of employment within the health system in Uganda.

The respondent replies that he cannot seek an internal transfer because of job insecurity. The system is set up that once appointed to a district, a transfer involves having to resign from the public sector and reapply as a new applicant – an almost impossible choice in a country where less than 5% of the work force is employed in public sector employment. Poverty, job insecurity, and a lack of alternatives were the main reason why these workers remained in their positions despite the challenges.

The second excerpt conveys a sense of frustration and powerlessness. The participant reveals how the participant attempted to bring an issues surrounding infection control (that he believes are important) to a higher level for the past five years. The researcher interprets this as a sense of powerlessness. Ironically, these same personnel are depended upon during the management and control of epidemics, yet they have no power to influence basic protective precautions. The third excerpt refers to the overcrowded and poor living conditions available for the health workers in Bundibugyo. This was also confirmed through direct observation.

During the data collection phase, the researcher was frequently asked by health care workers if she knew of any job opportunities in Kampala or her home country. A desire to seek new opportunities or improved remuneration seemed to influence why some staff members sought opportunities to partake in the West African outbreak. A study undertaken by Chimwaza *et al.*, (2014) among health care workers in Malawi highlighted several demotivational factors that shared similar themes to those identified in Bundibugyo and Kibaale. These included financial issues, housing and infrastructure, lack of training and promotional opportunities, workload, lack of resources and geographical isolation. Bundibugyo has the added threat of frequent insecurity and both case study sites have the potential for EVD re-emergence.

4.3.1.5 Experiences of despair and helplessness

The final group of codes under this category of ‘response hierarchies’ includes the survivors and relatives of those who died during the EVD outbreaks. The excerpts convey the sense of despair and helplessness experienced by those directly affected who were powerless to change the outcome of events and the consequences that linger on several years later.

Data Presentation 4.2.1.5
Theme 2: Structural Determinants of Delayed Diagnosis
Category 1: Response Hierarchies
Open Code 5: Experiences of Despair & Helplessness

- *in one single day they buried four people...from there she actually had no, any other feeling now, normal feeling, because she was only seeing these people were dying time and again and she reached at a certain level she just gave up with life because she doesn't know what is happening and she doesn't have any ability to do anything now to resist this (IDI, K10)*
 - *the effects like the orphans, the widows and some bit of stigma and trauma whereby, I remember of one person who lost a husband and a daughter and up to now that person has not stabilised properly, so some of the effects of Ebola are still affecting the families which were affected (IDI, B4)*
 - *my eyes have gone, I cried my sister and the eyes are [] I cried for the whole 2 years, I could not work, I could cry anytime because she could help me (IDI, B11)*
 - *We are dead, all of the victims there, because of course we went there, there was no treatment, the only treatment was death, so whoever would go, because me when I entered there we lost a big nursing assistant, Rose (?), as soon as I entered the ward isolation she died, so that one disturbed my brains now, psychologically (IDI, B12)*
 - *so she said she was, she didn't have anything now to reason like getting feared, she wasn't worried, because what she thought was only one, her mother has already died, even if she dies there is no problem, she will (IDI, K9)*
-

The first excerpt from a mother who lost twelve family members expresses her despair over the overwhelming trauma she experienced during the Kibaale outbreak.

In the second and third excerpts refer to the long-term trauma experienced by families who lost loved ones seven years after the Bundibugyo outbreak in 2007. The fourth excerpt refers to the despair experienced by a survivor of the virus who believed that death was inevitable. The fifth excerpt conveys a sense of giving up on the hope of surviving infection following the death of her mother.

Powerlessness usually occurs where firm hierarchal organisations are positioned at the top of a society and determine the environment for those at the bottom. Because of the hierarchical organisation of the society, the voices of the affected communities that experience these events and a magnitude of equally devastating events do not reach the level of policy and are absent from the national and global narrative.

4.3.2 Weak Health System

The outcome of EVD outbreaks is largely due to the capacity of the health system to respond in controlling and managing them. The mass mortality rate that resulted from the unprecedented West African outbreak was largely due to the inadequate health systems and lack of resources in the affected countries underlined by extreme poverty. In the case

of Sierra Leone, years of civil war resulted in an almost non-existence of a health system at the time the EVD emerged (Boozery, Farmer & Jha, 2014).

Data Presentation 4.2.2
Theme 2: Structural Determinants of Delayed Diagnosis
Category 2: Weak Health Systems

(i)	Non-preparedness	(Data Presentation 4.2.2.1)
(ii)	Overburdened health system	(Data Presentation 4.2.2.2)
(iii)	Poor surveillance and diagnostic capacity	(Data Presentation 4.2.2.3)
(iv)	Lack of resources to implement infection control	(Data Presentation 4.2.2.4)
(v)	Lack of support to health workers	(Data Presentation 4.2.2.5)
(vi)	Endemic burden of disease	(Data Presentation 4.2.2.6)

4.3.2.1 Unpreparedness

The findings convey the resources available to the health workers to manage an unknown infectious disease in Bundibugyo and Kibaale as recalled by the participants at the time EVD emerged in 2007 and 2012 respectively.

Data Presentation 4.2.2.1
Theme 2: Structural Determinants of Delayed Diagnosis
Category 2: Weak Health Systems
Open Code 1: Unpreparedness

- *The challenge was understaffing because we started few here we had to work day and night no rest, those were the challenges (IDI, K4)*

Out of stock so whenever we

- *We had nothing exactly [] yeah just normal soap [] we didn't have even gloves in the whole district, because they were out of stock so whenever we could get a patient we could ask a patient to buy some gloves so that we, we manage using those gloves and they were a bit expensive (IDI, B2)*
- *We didn't have, cause even uniform because we were just like we are, we didn't even have uniform, so even gloves were not there by that time, patients were just buying, patients could buy themselves gloves (IDI, B2)*
- *The challenge which came immediately after that [diagnosis of Ebola] was we had no funds available, they told me the budget line is too low [] after reducing our budget we don't provide meals for our patients, so that one also became a big challenge to us [] we had these grumpy nuts, between us we started giving and then even those who were strong started rioting and nobody would provide them with food. Eh it was a real problem (IDI, K11)*



Unused laundrette, Kagadi Hospital, Kibaale District 2014 Source: Researcher (DO, P4)

4.3.2.2 Overburdened systems

In addition to the weaknesses within the health, facilities to respond to epidemics the systems themselves were overburdened on a daily basis by the existing burden of endemic diseases affecting a rapidly expanding population.

Data Presentation 4.2.2.2

Theme 2: Structural Determinants of Delayed Diagnosis

Category 2: Weak Health Systems

Open Code 2: Overburdened health System

- *Like the hospital was supposed to be having at least a hundred patients at the time it was constructed in the sixties [] but now it is getting over 300 [] they have wards but they are overwhelmed by patients, you find some patients are on the floor, the space is not enough (IDI, B10)*
- *We run out of supplies most of the time, because they supply quarterly and the supplies are not enough for the quarter. It's a 100 bed hospital but most of the time you are having more than 200 in-... 300 in-patients and then the outpatient is so high, it is so so high so the supplies are completely insufficient and even then, even the funds for other services, for the last 10 years they have been funding the same amount of money as capitation work as being given by central government (IDI, K1)*
- *The Congolese refugees, they drowned in the water and we had more than 200 bodies brought here [] they were escaping from their side there, coming to Bundibugyo [] yeah, so it was a disaster [] they were taken across Congo but those that came after 72 hours they refused to bury them so they were brought back [] so now the town Council could not get land and after here and there they decided to borrow a piece of hospital land, its just across somewhere, that's where they buried them (IDI, B7)*
- *You even find that the water system is breaking down in health facilities in Bundibugyo Hospital, and as I said Bundibugyo Hospital was constructed in 1969, the infrastructure in Bundibugyo hospital in terms of staff quarters, in the water system and the toilet system is very poor, leaves a lot*

to be desired. Yes so the sanitation in Bundibugyo Hospital is extremely poor whereby the buildings are very old and the sewage line blocks frequently and there is overcrowding in the staff quarters, can no longer cope with the number of the staff they are supposed to accommodate (IDI, B4).



Morgue Kigadi General Hospital, Kibaale District 2014

Source: Researcher (DO, P5)

4.3.2.3 Poor surveillance and diagnostic capacity

Data Presentation 4.2.2.3

Theme 2: Structural Determinants of Delayed Diagnosis

Category 2: Weak health system

Open Code 3: Poor surveillance and diagnostic capacity

- *We are supposed to use money from surveillance but we don't get money from surveillance and it is WHO that is supposed to sponsor such things [] you fail to do surveillance work, all the health units in the district you are supposed to do active surveys and disease surveillance, but this money is never enough at times there is not even means of transport like transporting that sample going to Kampala (IDI, B2)*
 - *Really minimal procedures they could do, some microscopy, some bit of parasitology, and these mainly antigen antibody tests, I don't know how you want to put them [] We can't do good microscopy, I mean microbiology and parasitology (IDI, K1)*
 - *The team came with a preliminary diagnosis where they said this could have been worms, actually I remember the first preliminary diagnosis was concluded as worms but it was not concluded by that team because the Ministry responded immediately and came the following day, (IDI, B6)*
-

Despite the levels of health service delivery outlined in the Health Sector Strategic Plan (Chapter one, Table 1.2) that suggest a bottom up approach commencing at the village level, it became evident from the data that even if investigations of the reports of multiple deaths in the village were taken seriously the resources needed to commence surveillance or investigative procedures were not available.

4.3.2.4 Lack of resources to implement infection control

At the time of EVD emergence in Bundibugyo and Kibaale, the basic resources to control the spread of infection were not available as evidenced from the findings. Whilst the community was blamed for delaying to seek conventional health services, the capacity within those services to conduct surveillance, perform or confirm laboratory diagnosis of EVD were also not available. In the Bundibugyo case study the diagnostic equipment specific to identifying the virus was not, available in Uganda at that time and that the particular strain of virus, Ebola *Bundibugyo* (BEBOV) had not previously been identified.

Data Presentation 4.2.2.4

Theme 2: Structural Determinants of Delayed Diagnosis

Category 2: Weak Health Systems

Open Code 4: Lack of resources to implement infection control

- *I was taking some samples, stool samples, then in the process, we didn't have protectives, we didn't have gloves, so in the process I contracted the infection (IDI, B2)*
- *there was no clear cut information so they ended up bringing patients here and where we got a problem was because we lack some skills on infection control. [] It was unfortunate that during that time we had a shortage of gloves in the hospital here.....there wasn't enough gloves and of course no protective gear (IDI, B8)*
- *We are always improvising, at least we make sure there are gloves and aprons for the surgical, for the main theatre and some other procedures on the ward where, but you cant say there are enough gloves for every, for every staff on the ward (IDI, K1)*
- *The main problem we have with the water is the supply system has broken down. It was last repaired in 1998 I think [] So most of the systems, even the toilets are broken down and the pipes are blocked, [] so the cleanliness, hygiene and infection control is generally difficult when you don't have those water systems (IDI, K1)*
- *we have a number of cleaners, at least one cleaner is attached to one ward, so they normally clean in the morning, so you find from the morning up to the evening, you find the ward being dirty, they have to wait until the next what [day] (IDI, K4)*



Non-functioning incinerators, Kigadi Hospital, Kibaale District 2014 Source: Researcher (DO, P6)

4.3.2.5 Lack of support to health workers

Lack of intervention and support resulted in the deaths of health care workers who also experienced powerlessness in their efforts to seek government intervention.

Data Presentation 4.2.2.5
Theme 2: Structural Determinants of Delayed Diagnosis
Category 2: Weak Health Systems
Open Code 5: Lack of support to health workers

- *When we started the isolation unit the district got concerned that there is an outbreak of some infectious disease but then they didn't have much help, no support at that time, because even at the time we started we didn't have protectives. I remember one time at a DHT meeting, district health team meeting, I argued for provision of protectives but it was taken lightly (IDI, B5)*
 - *Ministry was only coming and it was stopping at that office over, say higher office, they would come and meet the CAO or the DHO and discuss how do we manage, that was all, but Ministry had not sent health workers support (IDI, B6)*
 - *it took a long time because imagine from August up to Novemeber people were dying there and they had not realised that it actually was Ebola, it took a long time (IDI, B8)*
 - *I: how long were you left in that situation before you got real intervention, how long was the hospital coping with...
R: it took some time actually, over 3 weeks (IDI, K11)*
-

4.3.2.6 Endemic burden of disease

Throughout the data several references were made to the endemic diseases in Bundibugyo and Kibaale districts. The most common diseases presented at the health facilities included malaria, diarrhoea, respiratory diseases and anaemia related to sickle cell disease. Several references were also made to previous cholera, measles and dysentery outbreaks within the camps hosting refugee populations and informal settlements near the shores of Lake Albert.

Data Presentation 4.2.2.6
Theme 2: Structural Determinants of Delayed Diagnosis
Category 2: Weak Health Systems
Open Code 6: Endemic burden of disease

- *When there is rain, in Bundibugyo, you expect malaria and diarrhoea, because of mosquitos around, stagnant waters and whatever. And with pneumonia when it is cold, children who are not covered well, they can develop cough and then pneumonia can come in (IDI, B11).*
- *We controlled it, it was a deadly type of dysentery because we lost more than 10 patients (IDI, B5)*
- *we used to experience cholera epidemics almost every year, actually for a very long period from like, from around 1980 up to 2000, also we used to have some cases of dysentery both amica and bacilla dysentery, also we had some epidemics of meningitis actually (IDI, B4)*
- *Yeah malaria is the most common, the reason is we have so many water channels in the district and people are thins but mostly the water channels are so many malaria and pneumonia, respiratory tract infection yeah and diarrhoeal diseases those are the commonest two and in addition to that we have so many sickle cell (IDI, B7)*
- *I remember, about the same time [EVD outbreak, 2012] we had cases of cholera at the lakeshore side so we had to go in and also manage that, at the same time there was some bloody diarrhoea, just dysentery which had occurred in a certain sub-county. (IDI, K7)*



Cholera Isolation Unit, Bundibugyo Hospital

Source: Researcher (DO, P2)

Respiratory conditions reflect between 12% and 20% of all morbidity cases in Bundibugyo and Kibaale respectively (UBOS, 2011). Several references were made to cholera outbreaks in both case studies. Uganda reports a maternal mortality ratio of 438 per 100,000 live births and an under five mortality of 90 per 1000 live births.

4.4 Social Realities

In the course of describing issues relating to events surrounding the outbreaks from both case studies, several references to the multi-dimensional features of poverty, the consequences of war and the limitations of fragile health systems emerged from the data. These codes and categories emerged into the theme of ‘a social epidemiology’ encompassing several social factors conducive to the emergence and spread of infectious diseases including EVD and conveying the contextual realities of both study sites. A social epidemiology for EVD emergence, amplification, and delayed diagnosis lies subordinated to a behaviour blame narrative outlined in theme one above.

Data Presentation 4.3

Theme 3: A Social Epidemiology

1. Poverty	(Data Presentation 4.3.1)
2. War	(Data Presentation 4.3.2)

4.4.1 Poverty

In pure economic terms, income poverty is defined as when a family’s income fails to meet an established threshold within a given country. Poverty is typically measured at household level. The international standard of extreme poverty is set to the possession of less than USD\$1 a day (UNESCO, 2017). A multidimensional perspective of poverty considers other features of deprivation including access to shelter, food, and healthcare. A number of these features emerged from the analysis.

Data Presentation 4.3.1

Theme 3: A Social Epidemiology

Category 1: Poverty

- (i) Population growth and food insecurity (Data Presentation 4.3.1.1)

- | | | |
|-------|-------------------------------------|-----------------------------|
| (ii) | Limited income sources | (Data Presentation 4.3.1.2) |
| (iii) | Barriers to accessing to healthcare | (Data Presentation 4.3.1.3) |
-

4.4.1.1 Population growth and food insecurity

Data Presentation 4.3.1.1
Theme 3: A Social Epidemiology
Category 1: Poverty
Open Code 1: Population growth and food insecurity

- *so you find people going to the forest anyhow, somebody finds a fruit in the bush, starts enjoying the fruit, which fruit are sometimes also eaten by wild animals (IDI, K9)*
 - Where we have had Ebola, the monkeys were coming into people's homes and sharing food, and the bats were even staying in some houses after their habitats were destroyed and bushes cleared for farming in the cases of Luweero, Kibaale, and Bundibugyo, among other areas. Dr Lwamafa says. (Ssekika/The Observer, 2012, DA)
 - *I will start with the broader factor which is poverty, you find that people are not fed properly for example they don't practice taking of a balanced diet and therefore their immunity is not always so strong and because of that they succumb to many diseases [] necessity is also contributing because as you can see in the market this animal protein is very expensive so I think in order to make ends meet, people are forced to go to the bush and hunt (IDI, B4)*
 - *People can't afford a kilogram of meat at the butchery but they think of going in the bush to hunt (IDI, B12)*
-

The majority of the population in Bundibugyo and Kibaale districts are rural based and rely on small-scale subsistence agriculture and informal trading for their livelihoods. Coffee, tea, cocoa and vanilla are among two important cash crops in Bundibugyo that bring in seasonal income but are highly vulnerable to market shocks and climate variations. Increased global demands for cocoa over the past decade have increased demands for production. As more agricultural land is used for the production of cash crops together with increasing populations and an influx of refugees from eastern DRC, limited resources remain for growing household needs. This results in the encroachment of agricultural land into wildlife buffer zones and puts people in closer contact with wildlife habitats (Chetri, 2004). This issue is conveyed in the first two excerpts. As previously outlined, the index case in the Kibaale case study was clearing forestland with her husband when she fell sick (Okware, 2015).

Excerpts three and four offer a social perspective to hunting behaviour in terms of the contextual reality of poverty, “*people can't afford a kilogram of meat*”. References in the data were frequently made towards hunting as an alternative for those who could not afford to purchase meat from a butcher. Whilst some communities in Africa hunt and eat bush

meat for consumption, this view often supersedes the social reality that hunting is a livelihood and an accessible protein source. In some contexts, it is cultural but in others, it is a result of poverty and food insecurity. In chapter, four (Section 4.2.1.1) it was outlined how engagement in agricultural practices in environments where the virus was naturally present was sufficient to be a risk factor.

4.4.1.2 Limited income sources

Data from both case study sites refer to poor public salaries and budget cuts and stagnation over the past decade. Several references in the interviews are made towards school fees, transport costs, access to affordable health care, and the cost of a kilo of meat or a kilo of sugar.

Data Presentation 4.3.1.2
Theme 2: A Social Epidemiology
Category 1: Poverty
Open Code 2: Limited Income sources

- *It [government funding for public services] has been stagnant over years, like our salaries, even though the cost of living has increased.... a kilo of sugar has moved from even 800 what? to around 3000, 3500 [Ugandan shillings] but the salaries have not [increased] (IDI, K11)*
 - *She is complaining the child has no school fees and maybe perhaps maybe they have no salt and these are the hard of daily basis, she said I shouldn't be the one suffering, after all I'm old [] of course part of it [food they produce] they sell, they also need money but the fact is they have really suffered a lot according to her story (IDI, K9)*
 - *Back to work, after 2 months I tried to come back so, even if I was not walking as normally but according to the NGO's you know, these NGO's, they cant give you salary for long without [] you have to work so that you get something, that thing forced me to start working when I was not yet ok (IDI, K10)*
 - *They are getting greener pastures, see when they are outside here, like if they are here, they will just concentrate in the hospital, they don't get other private business where they can part time so that they can earn a living (IDI, B10)*
-

Despite an exponential rise in the population of Uganda over the past decade placing an increased burden on public services and increased costs of living, a corresponding rise in funding for public services and public salaries has not occurred. One health worker describes her financial challenges in the first excerpt above.

The second excerpt refers to a grandmother who lost nine of her family members to the EVD outbreak in Kibaale, leaving her with the burden of rearing her grandchildren alone. In a study in Liberia, the economic burden of Ebola orphans emerged as one of the many consequences of the West African outbreak (Abramowitz *et al.*, 2015). Community

support for orphans because of the war in Liberia was not an unfamiliar concept. This situation in general is also not unfamiliar to sub-Saharan Africa where for example, in 2003, 11 million children were orphaned to HIV resulting in an increasing economic and social burden borne by grandparents (UNICEF, 2003).

The third excerpt refers to a health care worker who returned to work following infection with EVD before her full recovery, as she feared losing her livelihood. The fourth excerpt refers to a conversation around some of the challenges of retaining doctors at rural public hospitals. The participant explains how doctors in urban locations would normally supplement poor public salaries by working in private clinics, yet this was not an option available in Bundibugyo.

4.4.1.3 Barriers to accessing healthcare

Uganda allocates less than 10% of its budget to health care, which is less than the 15% agreed in the Abuja Declaration by Heads of African States held in 2001 (WHO, 2014(h)). Most donor aid is not harmonized to the sector plan and is managed off-plan. This means that for the majority of Ugandans health care is paid for out of pocket.

Data Presentation 4.3.1.3
Theme 4: A Social Epidemiology
Category 1: Poverty
Open Code 3: Barriers to accessing healthcare

- *Actually they kept on taking their people there, going to Kagadi Hospital was a last resort since they had no money now, to take care of them cause a private hospital charged dearly [.] they were not having money to take care of them in private, they decided to transfer them to Kagadi Hospital and they all died from there (IDI, K9).*
- *The private ones are there, like we have some companies here [.] but still because of the income for the entire community is too low, to access those services [.] a caesarian section in those private goes as far as 500,000 [Ugandan shillings, approx. USD\$150] of which for a layman its hard to pay for that, that's why they prefer most of the help from the hospital [public hospital] (IDI, K2)*

The first excerpt conveys how accessing private health services is perceived as superior to public services (where informal fees are sometimes demanded anyway) and is frequently a first choice despite the costs. The woman interviewed during the study relayed that they had brought their family members to a private hospital (St. Ambrose) initially and subsequently admitted the remaining family members to Kagadi General Hospital when they could no longer afford to pay the fees at the private hospital. It is from here that suspicion was alerted to EVD. Contrary to the argument presented under theme one above that delays in accessing conventional health services was a cultural determinant. Accessing

formal health services, public or private in western Uganda does not guarantee access to ‘modern biomedicine’ or efficient diagnosis of all conditions. In chapter two, section 2.4.7 it was acknowledged that even during periods of targeted interventions to specifically manage EVD outbreaks; critical care treatment for patients in African settings is seldom sufficient. The second excerpt refers to how the majority of the population in Kibaale cannot afford access to private health services even for life threatening conditions.

4.4.2 War

The period from the commencement of the First Congo war in 1998 up to the time of writing spans both EVD outbreaks in this study. Several references in the data were made towards infectious disease outbreaks in the refugee camps and informal settlements along the lakeshore aligning with this period.

Data Presentation 4.3.2
Theme 3: A Social Epidemiology
Category 2: War

- | | | |
|------|--------------------|-----------------------------|
| (i) | Civilian Attacks | (Data Presentation 4.3.2.1) |
| (ii) | Human Displacement | (Data Presentation 4.3.2.2) |
-

4.4.2.1 Civilian attacks

Data Presentation 4.3.2.1
Theme 3: A Social Epidemiology
Category 2: War
Open Code 1: Civilian Attacks

- *in 1997, yes, 1997 up to around 2000 there was an insurgency caused by ADF, this is a rebel organisation called Allied Democratic Forces and this one forces people into camps (IDI, B4)*
 - At least 58 people were killed after gunmen launched a coordinated attack on police stations and military barracks (BBC, 2014, DA).
-

4.4.2.2 Human displacement

Hosting displaced populations from eastern DRC is an everyday contextual reality of Bundibugyo district for over two decades up to the time of writing. Registered refugees are

hosted in camps close to the border, others or non-registered populations migrate to settlements along the shores of Lake Albert.

Data Presentation 4.3.2.2
Theme 3: A Social Epidemiology
Category 2: War
Open Code 2: Human Displacement

- *With a new emergency under way in the North Kivu province of the Democratic Republic of the Congo, UNHCR and its partners have been rushing to help the tens of thousands of refugees who have fled the violence into western Uganda's Bundibugyo district (Dobbs & Edwards/UNHCR, 2013;DA).*
 - *As of Sunday night, the Uganda Red Cross had manually registered more than 66,000 people. UNHCR and its partners have completed joint assessment missions and begun moving food and non-food aid to the area. The refugees are living in any space available, including schools and with host families (UNHCR, 2013)*
 - *When fighting erupted between armed groups and government forces in the North Kivu province of Democratic Republic of Congo (DRC) in August 2007, it forced an estimated 10,000 Congolese to flee for safety over the border into Uganda. Separated from their homes and livelihoods and lacking food and water on the Ugandan side, these refugees spent the next weeks risking trips back and forth over the border to retrieve supplies or to return home during relative lulls in the violence (Vick/MSF, 2008;DA).*
 - *By July 15, the Uganda Red Cross Society had registered some 65,000 refugees. Currently, the refugees are camping at Bubandi, Karela, Isonga and Kisaru primary schools and Bubandi sub-county headquarters land. However, the conditions at these centres are pathetic. There is inadequate water, food, and poor road access. At Bubandi primary school, there is one latrine block with four stances and the 10,000-litre water tank is non-functional (Ninsiima, 2013; DA).*
 - *In the Rwenzori region where over 80 percent of the population of Bundibugyo District are displaced - 120,000 displaced in 51 camps (UNOCHA, 2000, DA)*
 - *Up to 10,000 Congolese refugees have been sheltering in Uganda villages along the shores of Lake Albert since they fled fighting in eastern Congo in May when the Ugandan defence forces withdrew (UNHCR, 2003;DA).*
-

As previously mentioned the presence of refugees in western Uganda adds to the demand for available resources and the burden on an existing overburdened health system.

Refugees in western Uganda are the result of a protracted war in eastern DRC. Although the Ugandan government withdrew their forces from eastern DCR in 2003 when the Second Congo war was declared 'officially' over, internal conflict continues up to the time of writing. Excerpts 2 and four refer to the 66,000 refugees from neighbouring DRC who were registered in Bundibugyo district in 2013.

The political determinants of epidemic emergence is also acknowledged by reference to the consequences of insurgency and displaced populations into Uganda during the years

covering the wars in Eastern DRC. Because of increased conflict between the host fishing communities and more recent settlers from eastern DRC competing for fish as a food and a source of livelihood many refugees have been relocated to inland settlements by the Ugandan government and given small plots of agricultural land in western Ugandan districts including Kibaale. This also impedes on agricultural land.

4.4.2.3 Living conditions in refugee camps and informal settlements

In the Bundibugyo, case study direct observation identified many informal settlements around Bundibugyo town. A strong awareness of the connection between the living conditions and disease emergence was identified among the health workers living and working in Bundibugyo.

Data Presentation 4.3.2.3

Theme 3: A Social Epidemiology

Category 2: War

Open Code 3: Living Conditions in refugee camps and informal settlements

- *Our latrine coverage at that time was very low, below 50% and that means most of our community members were living in a polluted environment so that you would find the children infected or infested with worms because of living in a dirty environment (IDI, B4)*
 - *A lot of slums this side, even the other side there are slums and also the drainage in some areas is poor like that side as you are going to the border, there is a place which is a bit almost flat, so the drainage is very poor, so the intensity of water stagnating is high, so now this is an after-month [] that time the mosquitos were thriving (IDI, B7)*
 - *in the camps, hygiene was deplorable and also given the overcrowding resulting from people living in the camps with very poor infrastructure I'm sure it contributed to the cholera outbreaks and dysentery, it was common during those years... (IDI, B4)*
-

The first excerpt refers to the low latrine coverage and worm infestations in children. The second excerpt in data presentation 4.3.2.3 describes the environmental factors associated with the living conditions of informal settlements and the emergence of malaria. The third expert makes reference to the refugee crises from the First Congo war (1996-1998) conveying the living conditions and subsequent disease outbreaks experienced by the displaced populations during those years.

At the time of writing conditions for the refugees were conducive to disease outbreaks. This is logical in view of the large numbers of displaced persons from neighbouring DRC and the lack of basic services to host them. Direct observation around Bundibugyo

confirmed a large number of informal settlements on flat wetland areas surrounding the main town.

4.5 Chapter Summary

This chapter commenced by highlighting how culture was perceived from some data sources to be the main determinant for EVD emergence, transmission and delayed intervention. The majority of these perceptions were identified from data sources furthest from Bundibugyo and Kibaale at the national and global levels. A strong cultural epidemiology supporting understandings of EVD outbreaks was also described in the literature. The findings from this study offer several alternative explanations to EVD emergence and delayed intervention that emerged from the two case studies. Under the three themes presented in this, chapter alternative explanations emerged as rationale explanations for emergence, amplification, and delays in responses towards the two outbreaks in Bundibugyo and Kibaale. The death of health workers merited response at the district level but multiple deaths reported among isolated and socially marginalised communities over prolonged periods were overlooked. Despite a health sector structure from village to central level neither the political will nor the basic resources required to conduct surveillance and diagnostic investigations are available to respond effectively to major outbreaks. The health units themselves lack the basic resources and functioning systems required to prevent nosocomial infection between patients and staff. The CHOGM event presented a political determinant for delayed announcement of EVD in Bundibugyo in 2001.

A social epidemiology emerged from the descriptions of poverty and insecurity that comprise the contextual reality of living and working in Bundibugyo and Kibaale from where these outbreaks emerged. The social epidemiology is often subordinated to the cultural epidemiology of EVD outbreaks that dominates global literature yet are essential to understanding the health outcomes in any context. EVD outbreaks within Africa share similar social and political contexts. However, this seems to take a backseat when describing EVD outbreaks in the global literature. Chapter 5 continues with the hidden narratives that have attempted to convey the social realities and local voice from within these contexts beyond the spotlight of EVD interventions.

Chapter 5: Findings Part 2

Introduction 5.1

Chapter 5 is the second chapter presenting findings generated from analyses of the data. Again employing Strauss and Corbin's cyclic three step guideline outlined in chapter three the data was fragmented into coded segments and through the process of constant questioning and constant comparison groups and categories were formulated into themes. In this chapter, findings are presented under the remaining two themes: EVD Exceptionalisation and Agency. These two themes emerged from six categories and 28 open coded data fragments summarized in Table 5.1.

This chapter contributes towards addressing all four of the study objectives to understand the contextual realities, understandings, lived experiences, and aftermath of the EVD outbreaks that occurred in Bundibugyo and Kibaale in 2007 and 2012 respectively.

Table 5.1 Summary of themes and categories generated from the analysis

SUMMARY OF THEMES & CATEGORIES	
THEME 4: EVD Exceptionalisation	Data Presentation 5.4
1. A Humanitarian Response	Data Presentation 5.4.1
(i) EVD interventions	Data Presentation 5.4.1.1
(ii) EVD incentives	Data Presentation 5.4.1.2
(iii) Political will	Data Presentation 5.4.1.3
(iv) Identifying with EVD	Data Presentation 5.4.1.4
(v) Unmaking crises	Data Presentation 5.4.1.5
(vi) Ethical issues	Data Presentation 5.4.1.6
2. Consequences of EVD Exceptionalisation	Data Presentation 5.4.2
(i) Exceptional narratives & misdiagnosis	Data Presentation 5.4.2.1
(ii) Experiences of fear & anxiety	Data Presentation 5.4.2.2
(iii) Abandonment	Data Presentation 5.4.2.3
(iv) Containment and neglect	Data Presentation 5.4.2.4
(v) Stigma and social isolation	Data Presentation 5.4.2.5
(vi) Undervalued	Data Presentation 5.4.2.6
(vii) Undermining endemic disease	Data Presentation 5.4.2.7
3. Aftermath of the Crises	Data Presentation 5.4.3
(i) Reversion to unpreparedness	Data Presentation 5.4.3.1
(ii) Overwhelmed resources for everyday realities	Data Presentation 5.4.3.2
(iii) Non-functioning systems	Data Presentation 5.4.3.3

THEME 5: Empowerment	Data Presentation 5.5
1. Agency (i) Resilience (ii) Fluid therapy and local interventions (iii) Duty to patient care (iv) Motivation (v) Compassion	Data Presentation 5.5.1 Data Presentation 5.5.1.1 Data Presentation 5.5.1.2 Data presentation 5.5.1.3 Data Presentation 5.5.1.4 Data Presentation 5.5.1.5
2. Coping Mechanisms (i) Protecting others (ii) Self-preservation (iii) Faith (iv) Compassion (v) Social cohesion	Data Presentation 5.5.2 Data Presentation 5.5.2.1 Data Presentation 5.5.2.2 Data Presentation 5.5.2.3 Data Presentation 5.5.2.4 Data Presentation 5.5.2.5
3. Learned Mastery (i) Universal precautions (ii) Increased capacity (iii) Self-confidence	Data Presentation 5.5.3 Data Presentation 5.5.3.1 Data Presentation 5.5.3.2 Data Presentation 5.5.3.3

5.2 EVD Exceptionalisation

‘Disease exceptionalisation’ refers to the making or framing of a disease as different or unique from other diseases by building a narrative around it (Sontag, 2001; Smith & Whiteside, 2010). The theme of exceptionalisation emerged from the external interventions witnessed in response to the two EVD outbreaks in terms of financial flows, technical resources, and political will and media attention. The consequences of EVD exceptionalisation and the stark contrast observed in the aftermath of the temporary interventions also emerged as categories under this fourth main theme.

Data Presentation 5.4 Theme 4: EVD Exceptionalisation

-
- | | |
|---|---------------------------|
| (i) A Humanitarian Response | (Data Presentation 5.4.1) |
| (ii) Consequences of EVD Exceptionalisation | (Data Presentation 5.4.2) |
| (iii) Aftermath of the crises | (Data Presentation 5.4.3) |
-

5.2.1 A Humanitarian Response

The external response interventions witnessed during the 2007 and 2012 EVD outbreaks in western Uganda were in effect a temporary importation of a westernised public health response towards the management and control of a highly infectious disease [Data Presentation 5.4.1]. This rapid response involving the co-ordination of several donor organisations funded by external sources reflects a humanitarian response.

Data Presentation 5.4.1
Theme 4: EVD Exceptionalisation
Category 1: A Humanitarian Response

(i)	EVD interventions	(Data Presentation 5.4.1.1)
(ii)	EVD incentives	(Data Presentation 5.4.1.2)
(iii)	Political will	(Data Presentation 5.4.1.3)
(iv)	Identifying with EVD	(Data Presentation 5.4.1.4)
(v)	Unmaking crises	(Data Presentation 5.4.1.5)
(vi)	Ethical issues	(Data Presentation 5.4.1.6)

5.2.1.1 EVD interventions

The community only ever witnessed such an intervention between official announcement of EVD up until both outbreaks were declared over by the MoH and the WHO in 2008 and 2012 respectively. Under the revised IHR's, EVD is perceived as a 'public health emergency of international concern' and warrants international collaboration to respond particularly in resource poor contexts. International health responses come in the form of humanitarian interventions aimed at containing EVD outbreaks. Whilst it is understood that humanitarian responses represent emergency situations and therefore merit increased support it is also worth considering that from the perspective of those who live in Bundibugyo and Kibaale districts who experience daily challenges in the form of multiple deaths from endemic disease, cholera outbreaks and insecurity; for them the interventions witnessed towards the EVD outbreaks in 2007 and 2012 were exceptional. When compared to the scarcity of resources, lack of funding and lack of functioning systems that comprise 'normality' within the contexts of Bundibugyo and Kibaale health facilities.

Data Presentation 5.4.1.1
Theme 4: EVD Exceptionalisation
Category 1: A Humanitarian Response
Open Code 1: EVD Interventions

- *Like Unicef supplied us with these tents [] then WHO brought in the PPE's, then Médecins Sans Frontières, they brought manpower, they brought doctors, nurses and the other supplies like IV fluids, supportive drugs [] they set up an isolation site in the recommended way whereby we have got the suspected cases, the confirmed cases all those things were put in place by them (IDI, B2).*
- *Vehicles were always there, at least every team had a vehicle, like burial team had a double cabin [] then these people, the alert, the surveillance team had also a cabin [] even the district could hire some (IDI, B3).*
- *In Kibaale, I saw World Vision giving money to the tune of 40,000,000 (approximately USD\$16,000) [] the money was used for example, for taking the teams which were for contact following and then even collecting patients and suspects, ' cause we used to have a standby ambulance which whenever a field staff came across somebody who was sick, it didnt matter what signs that patient presents with, they would call the alert desk and the alert desk would send that ambulance to pick that patient (IDI, B4)*
- *Very many things were poured in here and we had a lot of support even from outside the country, the Médecins [Sans] Frontières, so we had gloves in full swing, gum boots, overs, and these solutions like chlorine" (IDI, K8)*
- *We also organise a team, we go there and we go with all our gadgets, we go and bury that person ourselves when we are protected [] we take paraffin and match box so that these clothing's we put on at the end of the day, the PPE's, we remove them, we burn them there and then, so we disinfect ourselves, the sprayer will not touch, the sprayers role is to keep our spray pump very clean and disinfect us before we enter the vehicle (IDI, K3)*
- *There was a technician from Uganda Virus Research Institute and one from Central Public Laboratories, they were taking blood samples from all these people and the following day a land cruiser went to Entebbe to have those samples done, by the end of the day we could get results either by mail or by phone and then the written papers the following day (IDI, K7).*
- *CNN was the other end, WBS and UPS they were here [] we had very many actually (IDI, K2)*



WHO donated vehicle donated during the EVD outbreak Source: Researcher 2014, (DO, P3)

The WHO supplied Bundibugyo district with three Toyota double cabin pick-up vehicles in 2007. These were used for transferring suspected cases to the isolation units for investigation. Several vehicles were also rented during that period for various services including transferring samples to Uganda Virus Research Institute at Entebbe for rapid analyses during the outbreak period. One participant describes the burial system

implemented during the EVD intervention periods in 2012. This included training of burial teams, provision of vehicles and fuel, protective clothing, disinfection sprayers and supervised burials. Events in Kibaale district in 2012 were covered by international news channels posted directly outside the hospital compound during the period of the outbreak. These interventions convey how organised and functioning support systems, not otherwise available, were imported in to Bundibugyo and Kibaale to implement the recommended WHO infection control measures outlined in chapter two (Section 2.4.8.1). Together these interventions demonstrate an example of a targeted disease intervention, where resources are made available to specifically tackle a single disease supported with financial flows and political will.

5.2.1.2 EVD Incentives

Incentives were offered to health workers to return to work during the outbreak and to retain those who had remained following announcement of EVD. The following excerpt refers to how incentives in the form of food and money were offered to the health workers during the intervention period for retention.

Data Presentation 5.4.1.2
Theme 4: EVD Exceptionalisation
Category 1: A Humanitarian Response
Open Code 2: EVD Incentives

- *They [i.e. the external organisations] started motivating us, getting us some food-stuffs, even money, but there was some good money they were giving us at that time, at least to make us [] to encourage us to continue (IDIB9)*
 - *There was motivation in terms of payment so for us we who were on the ground earlier were not part of that team, not until it was our RDC, the political in -charge who said “no, you cannot exclude our people who have already suffered because they worked and tried without money to control the situation” but now you come with motivation and you exclude them, that is not good (IDI, B6)*
 - *Some were being paid by, like the medical personnel, those ones were being paid by the Ministry, for us we had gone there just on contract and we were recruited by MSF (IDI, K6)*
-

5.2.1.3 Political will

Across both case studies references were made towards political will and a subsequent rapid improvement in the support for resources and functioning services during the intervention periods that would not normally be available.

Data Presentation 5.4.1.3
Theme 2: EVD Exceptionalisation
Category 1: A Humanitarian Response
Open Code 3: Political Will

- *They had very many, very many people joined and they had some staff from the Ministry of Health, from different hospital, even some from Bundibugyo (IDI, K8)*
 - *And then [] receiving the patients, formation of those committees, the triage committee, clinical management, logistics and whatever and we had already informed our political leaders and our administrative leaders to assist us, mobilise vehicles, mobilise fuel, you know those things, quick, quick things...(IDI, K7)*
 - *The Minister promised he was going to make a follow up to that one, then on Wednesday, the coming Wednesday a team from Kampala came from the Ministry of Health and we took samples from those patients who were here [] we requested to know what the results so that by Thursday they can give (IDI, K2)*
 - *Not as an individual [] because you cannot just change the public thinking, public way of doing things because you are a doctor, because you are a scientist what? You need other arms of the public, you need the security, you need the political will as long as you are able to work together with those things, I believe I could do something to change, yeah (IDI, B6)*
 - *then even the politicians, members of parliament, the chairman LC5 had to go to the Ministry and that's when parliament had to put in pressure, they had to send a team from the Ministry to do the necessary intervention (IDI, B8)*
-

5.2.1.4 Identifying with EVD

A sense of identity associated with the management of the EVD outbreaks was identified in the data. There was a perception among some of the participants that having managed the outbreaks successfully they had acquired international recognition and were highly sought after to assist in other EVD outbreaks across Africa. Identifying with EVD emerged as a category under exceptionalisation because it was perceived as having a superior or 'international' role among infectious disease management when compared with other endemic infectious diseases such as cholera or measles. Data Presentation 5.4.1.4 conveys some excerpts related to pride and recognition.

Data Presentation 5.4.1.4
Theme 2: EVD Exceptionalisation
Category 1: A Humanitarian Response
Open Code 4: Identifying with EVD

- *It is our blood who told the nation that it is Ebola positive (IDI, B1)*
- *I'll attempt to co-ordinate with many of my friends who for example I acquired during that exercise of controlling Ebola and I also have some friends in USA. Because even these people from WHO know me personally...but I would wish to be an international public health worker (IDI, B4)*

- *Uganda by then we were recognised, we have something even in the MS's [medical supervisors] office, but in addition to that, we had certificates of recognition and already sending in messages to people, some of us are supposed to be going to Liberia, that is some recognition (IDI, K11).*
-

The first excerpt conveys how one of the participants felt proud that the blood samples provided by him and his colleagues were the ones that led to a confirmed diagnosis and an official announcement of EVD in Uganda in 2007. In the second excerpt, the participant associates his work with Ebola as having professional and social value and that his involvement with it could lead towards career progression within the 'international' arena. The third excerpt conveys how the participant perceives that Ugandan health workers with experience in managing EVD are internationally recognised. The media and political attention that captured the outbreaks also go a long way towards forming these perceptions. Some patients who survived infection were asked to partake in radio-talk shows and were given a paid position in NGO's to partake in psychosocial counselling to speak about their experience and 'de-stigmatised' the disease among the community. Selection for interview for this research was also perceived by some of the participants as a sense of recognition. The interviews took place during the West African outbreak and some participants felt that they were being sought after as potential candidates to work in West Africa. A similar level of pride or heroism was not expressed towards managing cholera or typhoid epidemics as outlined below in Data Presentation 5.4.2.7.

5.2.1.5 Unmaking Crises

Following the locally witnessed interventions towards the two EVD outbreaks that could be described as a humanitarian response, a series of events were also implemented following the declaration that the outbreaks were officially over that could be described as 'unmaking the crises'.

Data Presentation 5.4.1.5
Theme 2: EVD Exceptionalisation
Category 1: A Humanitarian Response
Open Code 5: Unmaking Crises

- *Yeah, you see we had kind of a celebration, so we told the community people to come at the health centre, it was a big celebration, so we celebrated, district people came, also WHO came, the Medicines sans Frontiers also came and they passed a message that the disease is now out completely of the district so people could come normally to the hospital to get some services and people started coming (IDI, B2)*

- *And then they removed the tents and, everything most of the things were burnt [] immediately when they left then some of those things were no longer being provided but at least things like hand washing they were trying to emphasise on that thing, hand washing yeah (IDI, B3)*



*Remnants of changing rooms for personnel protective equipment at Kagadi General Hospital, Kibaale, 2014.
Source: Researcher 2014 (DO, K7)*

These events were an attempt to remove the association of the public health units with EVD and revert everything back to ‘normal’ or how it was before the interventions.

5.2.1.6 Ethical issues

Several participants in the study reported that they felt deceived or exploited by events they experienced during the outbreaks. Survivors from both case studies identified two areas in particular where these claims were supported; the first related to the taking of blood samples by ‘outsiders’ and the second referred to the denial of compensation packages due to them from the MoH following the outbreaks [Data Presentation 5.4.1.6].

Data Presentation 5.4.1.6
Theme 2: EVD Exceptionalisation
Category 1: A Humanitarian Response
Open Code 6: Ethical Issues

- *They didn’t receive any result, they didn’t know what is happening, they were not informed about the result, what they are assured of was that they were brought and they would just receive a team*

of the *wazungus* [white people], they would come here and pick blood samples and they didn't know what was [for] (IDI, K9).

- *Even these people, I don't know if you are connected with them? these people used to come here and pick my blood, my sample [] people from outside (outside Uganda) and doctor from Kampala [] but they were saying that in June, they come back and tell me the last, whatever, the last results, up to now I have never seen them? [] they come to Kampala, they connect with that doctor, they would travel to come this end and get the sample [] they say they are testing antibodies, what? [] that form they don't, they take it, they don't leave it [] they give me a bottle of soda and they go (IDI, K10)*
 - *CDC was responsible for receiving them [] so I would go with them, actually they are the ones who trained me how to carry out those and as soon as I come from the field I would hand over to them (IDI, K3)*
 - *I went there (the Ministry for Health, Kampala) this year in Feb, when I went there again, there is another man who lost a wife, this man, he went in the Ministry, they tell him that "you people we have already paid your money now why are you looking here?, he said " no we have never seen that money". [] and since then they didn't respond (IDI, K9).*
 - *Even the drivers became a problem, even those ones who came from the centre, they would tell us that " Ah we are going to such and such a place to collect a person we want fuel" [] By that time [] we couldn't identify immediately they said "we came even before we want our allowances" so it became a big problem [] and another problem which we faced was safety [meaning security] of these protective gears, the gum boots and the what what, those ones would come copting to be volunteers, go to the store, pick the gum boots disappear with them (IDI, K2)*
-

The first two excerpts refer to participants who had their blood samples taken by 'outsiders' but the purpose for these procedures remained unclear and none of the participants had received feedback or results following the exercise. In the first excerpt the Kibaale index explained how they, the few remaining family members received several visits from '*wazungus*' [white people] who took their blood samples.

In the second excerpt the participant, from a medical background understood that the samples were being tested for antibodies; "*they say they are testing antibodies*" but assumed it was for monitoring her recovery. The participant did not receive any further information or feedback as she had been originally informed. When asked if she received any compensation for providing her blood sample, she claimed to have received a soda. A 'soda' in Uganda usually refers to a cash tip equivalent to the value of a bottle of soda, about 1000 Ugandan shillings (approximately USD\$0.33c). From the reference to 'wazungu', "they are from outside" and a question to the researcher "I don't know if you are connected with them?" it can be interpreted that these were non-African researchers. In the third excerpt, a participant reports how he was trained by the CDC to collect and dispense samples to them during the Kibaale outbreak.

The second excerpt makes reference to a consent form but there is little understanding of its meaning or a copy of its content "*that form [] they take it, they don't leave it*". These events identify issues related to medical ethics and the vulnerability of the host

communities during EVD outbreaks. In 2010, the Centre for Disease Control was awarded a patent on the commercial product EboBun for vaccine preparation (Patent No. CA2741523A). In this study, reference was made by some of the participants that blood samples taken from them and other patients were deposited to CDC, Atlanta.

they were taken to Entebbe [] but then I understand they were taken to CDC Atlanta, it was diagnosed from CDC Atlanta (IDI, B5)

A second main area where issues of ethics emerged was related to the failure to receive compensation packages that were due to victims of the disease from the MoH, referred to in the third excerpt. Following up on the compensation involved travelling from Bundibugyo or Kibaale to the MoH Headquarters in Kampala incurring additional costs and further bureaucratic barriers for the participants. The fourth excerpt is one example of reports on incidents where ‘volunteers’ made excessive claims for day allowances, fuel and transport and how gumboots were stolen.

5.2.2 Consequences of EVD Exceptionalisation

As outlined above exceptionalisation of EVD emerged from the findings from multiple factors including how external interventions were locally perceived and how this together with western narratives influenced perceptions about the disease being exceptional. The exceptionalisation of EVD had consequences that affected those who experienced it. The next section explores these consequences.

Data Presentation 5.4.2	
Theme 4: EVD Exceptionalisation	
Category 2: Consequences of EVD Exceptionalisation	
Exceptional narratives & misdiagnosis	(Data Presentation 5.4.2.1)
Experiences of fear & anxiety	(Data Presentation 5.4.2.2)
Abandonment	(Data Presentation 5.4.2.3)
Containment & Neglect	(Data Presentation 5.4.2.4)
Stigma & Social Isolation	(Data Presentation 5.4.2.5)
Undervalued	(Data Presentation 5.4.2.6)

5.2.2.1 Exceptional narratives and misdiagnosis

Prior to 2014, EVD was inappropriately referred to as a ‘haemorrhagic virus’ stemming from the imagery and exaggerated accounts of the disease portrayed in western media described in chapter two (Section 2.5.3). It is now known that major haemorrhagic features of the disease appear in less than 7% of cases, usually preceding the death of the patient (Bah *et al.*, 2015; Bitekyerezo *et al.*, 2002). Delays in diagnosing EVD in both case studies referred to misunderstanding about the clinical features of the disease previously believed to be presenting with major haemorrhagic features. Even before the unprecedented West African outbreak the scientific literature framed EVD as an exceptional disease and classified it as a ‘haemorrhagic virus’.

Another important reason for delays in diagnosis and response to the two EVD outbreaks was that the presenting clinical features of the disease were not dissimilar to several common endemic conditions that presented in the context of western Uganda including malaria, typhoid, and diphtheria. Data Presentation 4.1.3.4 convey how patients infected with EVD presented to the health care workers in 2007 and 2012.

Data Presentation 5.4.2.1

Theme 4: EVD Exceptionalisation

Category 2: Consequences of EVD Exceptionalisation

Open Code 1: Exceptional narratives and misdiagnosis

- Blood fills the intestines, the digestive tract and the bladder, spilling out of the nose, eyes and mouth...and the corpse of a body remains ‘hot’ for days (Hammer, CDC, 2012; DA)
 - *The gruesome death that frequently accompanies Ebola Haemorrhagic Fever has ensured that the disease is etched deeply in the public imagination (Kinsman, 2012)*
 - *You know when you are treating non-responding fevers, that’s when you start suspecting viral infections, but it was not in our minds that it could have been Ebola virus, because there was no haemorrhage anywhere [] There was just these fevers mainly and vomiting (IDI, K1)*
 - *Actually in this clinical presentation, they didn’t have bloody diarrhoea, they had more abdominal pain and then some diarrhoea, headache, fever was persistent, sweating of course finally they would get into some mental confusion, sometime before they die [] in my mind first was maybe this could be some form of either cerebrum meningitis or encephalitis, some of these things was running in my head (IDI, K7)*
 - *Even in Bundibugyo they said it wasn’t a typical haemorrhagic [virus], you know the haemorrhage wasn’t there (IDI, K7)*
 - *For him he said I have malaria cases, I’m treating, I discharge but they keep coming back, other have started dying and they even have diarrhoea. Actually there was nothing like an idea of any knowledge, that knowledge of haemorrhagic fever (IDI, B6)*
-

Data presentation 5.4.2.1 demonstrates the contrast between a westernised narrative that frequently appeared in the mass media and the clinical realities witnessed by frontline health workers in Bundibugyo and Kibaale in 2007 and 2012. The term ‘Ebola Haemorrhagic Virus’ remained in use in both scientific and popular literature up until 2014 and cases presenting without haemorrhagic symptoms in the interim continued to be misdiagnosed and referred to retrospectively as ‘atypical’ (Alsop, 2007). The misinformation disseminated about EVD since it was first reported in 1976 was not revisited for almost forty years when clinical observations were captured by western medics working in Ebola units during the West African outbreak in 2014 (Aylward *et al.*, 2014).

5.2.2.2 Experiences of fear and anxiety

Fear is defined as a feeling of apprehension or alarm in response to an external source of danger (Dox & Melloni, 1998). The official announcement of EVD in both outbreaks was the trigger that incited fear into the community resulting in mass abandonment of health workers and patients from the health facilities initially. It is not known whether this fear stemmed from access to the exceptional rhetoric portrayed by western media highlighted in the previous section that filtered through to national media reporting or through knowledge and anecdotal reports from previous outbreaks in northern Uganda and DRC (Kinsman, 2012). The following Data Presentation (5.4.2.2) demonstrates the experiences of fear among the health workers and a patient who was admitted to an isolation unit at Bundibugyo Hospital. The patient’s response portrays how he perceived death to be an inevitable outcome of infection.

Data Presentation 5.4.2.2
Theme 4: EVD Exceptionalisation
Category 2: Consequences of EVD Exceptionalisation
Open Code 2: Experiences of fear and anxiety

- *the experience I had by that time after seeing the rampant condition coming from the same area, the same people getting the same disease [] so as health workers we were scared, we say what is this? (IDI, B1)*

- *we were afraid actually, we would even come here (staff office) sit and get the sleep because at night you wouldn't sleep, we would leave here past midnight, by 7 you are already here now the tension went down because now after 21 days everybody saw, was in the capacity of what? of sustaining himself or herself (IDI, K2)*
 - *it was very scaring, very scaring because sometimes you would [] have some abdominal upset, you feel maybe, you get scared, maybe the thing have started, sometimes you get nauseated, you feel like vomiting, you think like "Ah I think I have started" then you go in for some drugs [] we were very scared of it (IDI, B10).*
 - *There was total silence, but all of us just kept quite, some of us were sweating, some we were just confused we were just staring [] we were real shocked ... very very frightening and now people were saying eh the other one could have, so every patient you have touched is now like an Ebola victim [] in fact even in our houses we were just looking up and said "now, what next, tomorrow I'm the one, tomorrow I'm the one" (IDI, K10)*
 - *they asked me to give them the history, so when they saw the eyes, also red he said "this one's a victim", so when he mentioned it, immediately I vomited []the stress we got was so so serious, because there was one patient who died called X, his bed was here, mine was here but he died when I was seeing like this [] I became mad by the way, hostile, I moved out of the isolation ward, I passed through here, I go and die from my house (IDI, B12)*
-

5.2.2.3 Abandonment

In the study, the concept of fear was generated from the perception that infection with EVD resulted in an imminent and gruesome death and there was no cure. The resultant fear manifested as panic and health workers and patients abandoned health units [Data Presentation 5.4.2.3]. This resulted in several negative consequences for those who became infected and their families.

Data Presentation 5.4.2.3
Theme 4: EVD Exceptionalisation
Category 2: Consequences of EVD Exceptionalisation
Open Code 3: Abandonment

- *we felt we had been neglected, because the running away of the staff, the running away of some of the officers of the district of administration, there was a vacuum, now we are going to make the necessary intervention (IDI, B8)*
- *They (Kibaale case) had problems because all the health workers had run away, they ran away because of the other clinical officer [] So after the other clinical officer had died these other fellow nurses and what what they had to run away (IDI, B2)*
- *the patients, even the majority of staff left, they were split up and actually that one worsened the day when the doctor died, the other Dr. Kule died. That is the day when almost all health workers almost boycotted work. They simply said "no even that one died I cannot work, what about me the nurse, what about me" (IDI, B6)*
- *I tell you actually that day, actually what happened, after the announcement I also went away [.] I said "Ah it's too much now" (IDI. K2)*

- *Actually precisely about 30 -40% of the health workers just ran away, dispersed from the health facility [] the first impression of the health workers was anxiety and over a third of the health workers left, they just came back after about a week, when things have settled down, (IDI, K7)*
 - *The moment we created an isolation there, patients were just conscious, they all just left the hospital, because the disease was already nicknamed Kikosis meaning a disease from Kikyo [] The patients had the experience that people who were put in isolation they died in Kikyo and now that they have created this isolation there (Bundibugyo) and these workers are the same workers touching those and touching those so the patients decided to run away out of the hospital (IDI, B6)*
-

5.2.2.4 Containment and neglect

The category of ‘containment and neglect’ emerged from the data. The consequences of fear and a perception that without a cure death was inevitable resulted in a focus to identify and contain those infected. The outcome resulted in physical confinement, denial of treatment and in some case death for the infected patients including health workers who entered health units. The perception that there was no cure for EVD and that intervention had no rationale purpose beyond exposing health workers to infection was identified during the West African outbreak referred to as ‘therapeutic nihilism’ (Lamontague *et al.*, 2014, p.1565). This perception is likely to be a consequence of the misinformation in the scientific and popular literature that there is no cure for EVD.

Data Presentation 5.4.2.4
Theme 4: EVD Exceptionalisation
Category 2: Consequences of EVD Exceptionalisation
Open Code 4: Containment and Neglect

- *I’m telling you what happened in first week, like first 5 days they, we couldn’t allow people to go there (visitors to bring food), so people were there hungry in isolation room, even they quarrelled, “please you brought us here, you want us to die from here” (IDI, K4)*
- *As he was there [meaning Mulago Referral Hospital in Kampala] the disease intensified and then they identified him as a person who had come from Bundibugyo, Kikyo and he was having the same sickness as people who were dying in Kikyo [] Nobody treated him, people were fearing in Mulago, we can die from that doctor, if you touch you will also get sick, until he died they were just simply protecting him until he died (IDI, B6)*
- *When I reached there (Kagadi General Hospital) one day, the second day I got abortion [] I bled, I become anaemic [] I collapse, yeah I collapse, even the placenta, I got a retained placenta [] even the doctors, even some of the nurses were fearing us, when you tell them you, I have this and this, “let us come back”, they go, you (they) will not come, you will not see them, they go there and see, they were fearing the ward (IDI, K10)*



Ebola Patient at Kikyo Health Centre IV, Bundibugyo District (CDC, 2007, DA, P3)

Situations where patients suspected of having EVD lost control and independence over their personal freedom and right to healthcare were identified. In several incidents, patients suspected with EVD were admitted to isolation units as a means of preventing transmission of infection. Within the health units, they experienced neglect in terms of losing the basic provision to food and medical intervention.

The first excerpt in Data Presentation 5.4.2.4 conveys how the health authorities were engaged to organise an isolation area at Kagadi General Hospital for suspected Ebola patients. However once confined to the isolation unit the patients became aware that they were being contained involuntarily without adequate food. Health care workers feared to enter the isolation unit so that the patients were also denied treatment during this period. The second excerpt above refers to a doctor who had worked at Kikyo Health Centre IV and fell ill on returning to Kampala. He presented himself to Mulago Referral Hospital for treatment but following isolation medical treatment was not forthcoming due to fear among staff to approach him. The third excerpt refers to another health worker who became infected with EVD in the line of duty at another health centre. She conveys her experience in the isolation unit at Kagadi General Hospital in 2012 where nurses feared to intervene when she retained the placenta following a miscarriage because of the virus. Fortunately, for her, a doctor removed it eventually and from there, she recovered slowly. A similar situation was identified in a study in Liberia where children orphaned by Ebola during the West African epidemic were confined to quarantine and left to die because people feared to intervene.

Many of these children do not survive quarantine periods, they just cry to death because no one can provide care from the outset (Abramowitz, 2015, N.p)

Quarantine and confinement is not a new phenomenon for infectious disease control. As early as the 14th Century quarantine measures were implemented to prevent bubonic plague from crossing borders. Okware (2002) refers to “security agencies” that were involved in the coordination of community surveillance during the EVD outbreak in northern Uganda between 2000 and 2001.

The final data segment coded under this category presents a photograph of an emaciated patient who appears frightened, lying on a cast iron bed in a bare room constructed of clay walls and floor. A member from a spraying team has entered the ward to disinfect the environment wearing personnel protective equipment. This is a familiar image taken during EVD outbreaks that portrays the necessary precautionary measures required to manage and contain EVD. In terms of patient intervention, however the only visible form of treatment for the patient is a bottle of mineral water on a table beside the bed. No evidence of critical care management for the patient is evident in this image in terms of intravenous fluid therapy. The image also conveys the fear and isolation of the patient.

5.2.2.5 Stigma and social isolation

Fear also contributed to stigma and social isolation directed towards the survivors of EVD and the health workers who treated them by their community and family members [Data Presentation 5.4.2.5]. This resulted in social isolation; break down in marital relations and economic hardship.

Data Presentation 5.4.2.5
Theme 4: EVD Exceptionalisation
Category 2: Consequences of EVD Exceptionalisation
Open Code 5: Stigma and Social Isolation

Stigma from the Community

- *She said they felt very bad because after burying all these people, eventually the community turned like against them, they were isolated, so whoever would step here they would say “don’t bring for us Ebola, you get away, get away, get away” so they were isolated [] even up to now, very many people don’t want to come here, they still have that trauma and they believe the home is still unsafe (IDI, K9)*
- *Even during that time I traveled to Kampala in a bus, the bus was reaching here, Now from here we moved about 20 people up to Fort [Portal], the rest of the people got out. We remained three passengers [] we went up to Kampala only like that whatever stage we pass because the bus was*

labeled Bundibugyo-Kampala, they would say “Aah Ebola Bundibugyo bundibugyo, they would just shout at the driver don’t stop here don’t stop” and the driver up to Kampala three passengers (IDI, B6)

- *It was very different, in church people were not shaking hands, some closed their businesses. My daughter was not allowed home during that period. People in the bank were fearing money (IDI, B13)*
- *Before going back to the community, the first time I went to town, I had gone to shave but when people found me in the saloon, when I met them they all ran away, I was left alone in the saloon (IDI, B12)*

Stigma toward health workers

- *now the public were actually saying that it was health workers who infected them [] the town actually segregated health workers. When the other health workers died in Kikyo now they say, “these health workers handle sick people and as they come to town to the bank to your shop they will also greet you and they will infect you”. Actually we faced isolation [] I ... “you are from Bundibugyo, you don’t touch me” (IDI, B10)*
- *There was stigma to some other people because now like some of us whenever we could go in the village, they could say “Eh that one could be still having Ebola” (IDI, B2)*

Stigma within Families

- *It was so terrible, it was so terrible, even by the way even when we came from this end, when we went back to our families, people started to fear staying near us, having heard that you have been one of the people handling Ebola it was not simple for people to come near you [] even your family, they started fearing us (IDI, B3)*
- *At first, they feared they said “eh mammy you will bring the disease to us”, I said “no” but before I could wash myself thorough before I would enter the room (IDI, K8).*
- *We joked about it but it was a very hard time. For example, my husband would not have sex with me for a long time. The children were not allowed to come home. We were alone there, our neighbour had also died. The maid left and went home (IDI, B13).*
- *So I had my wife who even divorced because of the disease (IDI, B12) she*

Stigma and rejection by the community was experienced when carrying out everyday tasks. The fourth excerpt for example describes a survivors experience when going for a shave after being released from the isolation ward. Recognizing him as an Ebola victim, the customers fled from the premises in fear of contracting the disease. Health workers were also subjected to blame, stigma and isolation within the community. The experience of being isolated from family members was reported by several of the participants in both case studies and between marriage partners.

The findings of fear experienced by survivors of the outbreaks and the stigma and social isolation they experienced from the community and family members was similar to

findings from previous studies on EVD (Hewlett & Hewlett, 2005; Kinsman, 2012; Matua, 2014).

5.2.2.6 Feeling undervalued

Several health workers expressed feeling undervalued by the amount of compensation they received compared to risking their lives during the EVD outbreaks.

Data Presentation 5.4.2.6
Theme 4: EVD Exceptionalisation
Category 2: Consequences of EVD Exceptionalisation
Open Code 6: Undervalued

- *We just sacrifice ourselves, the probability of dying or not dying is half [] they were giving risk allowance of 30,000 (approx. USD\$8) but really this money was not so [] Like yesterday I heard over the news that one doctor has died in this outbreak of Sierra [Leone] now that one we have lost such a kind of doctor so at least they need to think of a good package at least so they can give some doctors and nurses who are just surrendering themselves to control such a deadly, like for us we just sacrificing ourselves going from Bundibugyo to Kibaale we just sacrifice ourselves, however WHO was giving us just 50,000 (approx.USD\$14) as risk allowance [] government could give us risk allowance of 30,000 [approx. \$8] But it wasn't worth it. It wasn't worth that (IDI, B2)*
- *Those survivors and families of the diseased for them they were compensated but health workers who worked, who did not get sick, and they survived they only got the other allowance which I told you, was 30,000 (approx. UDS\$8) [] I may not get the motivation to go (to take part in another outbreak) bearing in mind [] we were not considered, when very many very many health workers ran away totally, they left the hospital, these health units, then someone who risks himself should also be considered in such a way (IDI, B3)*
- *Many people don't have moral because of the pay, the pay is not sufficient to enable them to have a good living (IDI, B5)*
- *For me I like money also like anybody else but with the life and considering the money we were being given. If we had a choice from the beginning I would have chosen not to participate but with that comfort because I am a mother (IDI, K11)*
- *The Ministry for Health here does not recognise that department as an important department but the few years I have spent in that office I have found that office is actually very important and it is actually centre of interest because like when we go and perform histology and in performing histology we are the people who are providing the Ministry of Health with necessary information [] we can go and perform histology and in histology you can come up with a lot of findings (IDI, K3)*

The first excerpt conveys how a participant felt that health care workers should have been entitled to receive a better compensation package for risking their lives. The average daily risk allowance given to health care workers who were involved in the direct care to

infected patients within the isolation units was approximately 50,000 Ugandan shillings (approximately \$14 per day). This amount was cost shared between the international organisations and MoH.

Many participants expressed frustration with the government in terms of not receiving adequate, if any compensation for their efforts and the continued lack of funding for preparedness of future outbreaks even up to the time of data collection.

5.2.2.7 *Endemic disease undermined*

Data Presentation 5.4.2.7
Theme 4: EVD Exceptionalisation
Category 2: Consequences of EVD Exceptionalisation
Open Code 7: Undermining Endemic Disease

- *Maybe to rule out typhoid and what what, those ones were done in Bundibugyo but dealing with real blood (i.e. samples taken for diagnosing Ebola) it could be in Kampala (IDI, B2)*
- *Of course the committees for cholera also could be there but not with a similar kind of seriousness. Because for this one (Ebola) you would find the chairperson, LC5, the RDC and the Chief Administration Officer are all there (IDI, B4)*
- *the community they reported again some cases of diarrhoea with vomiting and people were suspicious, they thought maybe Ebola had come back but they rushed there, they removed the samples, they were taken to Entebbe, they checked it was nothing, it was sent again to Atlanta, they checked but it was nothing, only that time they confirmed it was typhoid (IDI, B8)*
- *Cholera has been the most seen, it is some sort of endemic really, it gets it periodically comes up especially around the lake region (IDI, K1)*

Undermining other health issues when compared with the attention given to real or suspected emergence or re-emergence of EVD also emerged from the findings. The use of the adjectives ‘usual’, ‘common’ or ‘normal’ were frequently used when describing other endemic disease outbreaks among some of the health care personnel. In the first excerpt, the participant refers to blood samples taken for diagnosing EVD as ‘real blood’ compared to blood samples to test for typhoid. The second excerpt compares the attendance of political leaders at committee meetings during the EVD outbreaks compared with similar meetings held during cholera epidemics. Association with cholera was perceived as less important or less serious and did not warrant political interest [*with a similar kind of seriousness*].

The third excerpt refers to an outbreak of bloody diarrhoea that occurred in a community near the shores of Lake Albert, soon after Bundibugyo was declared EVD free. The

suspicion that this could have been a possible re-emergence of EVD resulted in immediate response by the MoH. Taking the languid response exhibited towards infectious disease outbreaks in the community as evidenced under the category of marginalised communities in chapter four, it is worth considering whether action would have been forthcoming in the absence of a recent EVD outbreak. The perception that EVD warrants priority above other causes of morbidity and mortality among communities in Bundibugyo and Kibaale may be a consequence of disease exceptionalisation.

5.2.3 Aftermath of the Crises

<p>Data Presentation 5.4.3 Theme 4: EVD Exceptionalisation Category 3: Aftermath of the Crises</p>	
(i) Reversion to unpreparedness	(Data Presentation 5.4.3.1)
(ii) Overwhelmed resources for everyday realities	(Data Presentation 5.4.3.2)
(iii) Non-functioning systems	(Data Presentation 5.4.3.3)

5.2.3.1 Reversion to unpreparedness

Participants were asked their opinion on the current capacity of the health centre and hospitals if required to respond to another EVD outbreak. It emerged that the basic resources were not in place to respond at the time of data collection. At the time of data collection the state of preparedness in Bundibugyo and Kibaale had reverted to how it was before the EVD outbreaks as evidenced from Data presentation 5.4.3.1.

<p>Data Presentation 5.4.3.1 Theme 4: EVD Exceptionalisation Category 3: Aftermath of the crises Open Code 1: Reversion to unpreparedness</p>	
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- *Like in Kikyo they are not available, if there you might find around three pairs of gumboots where these cleaners are using, you may find two pairs in theatre whereby those theatre people use. But we need to have standby things maybe in stores, just waiting for any outbreak [] like protective gears, currently we don't have (IDI, B2)*
- *I would like if they could assist us with something like an incinerator because our waste disposal is a risk to us, that is a very big risk to us, yes (IDI, B3)*

- *The only things we have as protective equipment are gloves, because even aprons, in theatre we don't have real aprons or the PPE, personal protective equipments, we have only gloves, boots are for theatre and maternity ward and some few for cleaners so actually we are doing badly (IDI, B7)*
- *Its unfortunate, we would still go back through the same process, its like we didn't take good lessons [] we had got enough promise from the politicians, from everybody that the situation would not be the same again, but the situation is still the same, our sanitation is still very poor [] the systems are broken down [] that rapid response team they talked about it in the Ministry of Health but it was not functionalised (IDI, K1)*
- *No the resources are not there, they are not there because when we had Marburg outbreak, we sent a team from here, they didn't receive the resources so we had to give the resources to those ones [.] since that time after declaring Ebola free everything ceased so that is the problem, the major problem is funds because if we have funds we can get the protective gears (IDI, K2)*



Kikyo Health Centre IV, Bundibugyo District

Source: Researcher (DO, P1)

5.2.3.2 Overwhelmed resources for everyday realities

Data Presentation 5.4.3.2

Theme 4: EVD Exceptionalisation

Category 3: Aftermath of the crises

Open Code 2: Overwhelmed resources for everyday realities

- *Ok the whole year it is about 130 million (approx. USD\$36,000), so for the quarter you can work it out (IDI, K1) [reference to annual budget for Kibaale General Hospital serving a population of 500,000]*
- *So maintaining and retaining them [referring to 2 doctors] here, actually it has been a challenge to us except they are good, that they are ready to serve [] like of recent we have been admitting over 70 pedi [paediatric cases] [.] you find it has an extra of 50 compared to the planned one (IDI. K2)*
- *They have wards but they are overwhelmed by patients, you find some patients are on the floor, the space is not enough (IDI, B10)*

- *People have been suffering, they have been using their own transport, some have not been able to come to the hospital, so they have been getting complications from there, some have died [] incubator on the ward for babies (IDI, K8)*
 - *I would like to see when blood is available, every time blood is there [] because of the sickle cell, I always cry there when children are dying because of anaemia (IDI, B11)*
 - *One of the major problems is the wage bill, if the structure as provided by the government of Uganda is filled 100%, I think it would be fairly adequate for the task but overall we are operating at about 60% of the expected numbers of health workers in the structure [] we find more of these gaps at the lower level facilities [] the laboratory staff are harder to find in the lower facilities (IDI, K7)*
-

In 2014, seven years following the EVD outbreak in Bundibugyo and two years after the outbreak in Kibaale, the scarcity of basic resources was evident. The excerpts in Data Presentation 5.4.3.2 contrast harshly with the descriptions of the resources and systems imported during the EVD outbreaks in 2007 and 2012 above [Data Presentation 5.4.1.1]. The following sub-section describes an array of non-functioning systems observed in the aftermath compared with the situation experienced during the intervention phases of both outbreaks.

5.2.3.3 Non-functioning systems

Data Presentation 5.4.3.3
Theme 4: EVD Exceptionalisation
Category 3: Aftermath of the crises
Open Code 3: Non-functioning systems

- *only one vehicle is still sound, the other 3 have broken down. In fact the ambulance is still ok and one vehicle of the WHO, but the vehicles they gave to the hospital and Kikyo health centre have broken down (IDI, B4)*
- *I would like if they [the government] could assist us with something like an incinerator because our waste disposal is a risk to us [] the theatre we have but it is non-functionable because we have no medical doctor to do some of the procedures that are supposed to be done so some major operations we send them to Bundibugyo (IDI, B3)*
- *But the x-ray machine has been out of use for quite a long time, even right now it is out of use, it needs major servicing [] the mortuary is there, it's the only place with a morgue in the district but it also has a small capacity, but it can handle about 3 or 4 bodies [] sometimes bodies get stuck there so we have to appeal to the town council to assist us to dispose of those bodies, but as I talk now that morgue has no running water (IDI, K1)*
- *That (water and sanitation in the hospitals and health centres) is a sector which is performing very very badly. Yeah of course they dont fund, in all the health units. You even find that the water system is breaking down in health facilities in Bundibugyo Hospital, and as I said Bundibugyo Hospital was constructed in 1969, the infrastructure in Bundibugyo hospital in terms of staff quarters, in the water system and the toilet system is very poor, leaves a lot to be desired, yes so the sanitation in Bundibugyo Hospital is extremely poor whereby the buildings are very old and the*

sewage line blocks frequently and there is overcrowding, in the staff quarters can no longer cope with the number of the staff they are supposed to accommodate (IDI, B4)

- *Waste management is still a challenge, the incinerator is there built, central government contracted somebody to build it, the person who build seems to not have installed it completely and therefore it cannot function [] cleaning in the hospital is not done by the hospital workers or staff, the district contracts someone and then that contractor hires his people to come and clean the hospital, so the last person who had been cleaning actually did the worst because the incinerator was not working [] his people throw those things near the incinerator all these what? Needles so they just poured and they were not being burnt (IDI, B6)*

The capacity of the health units for epidemic preparedness and response was not improved as an outcome of the two EVD outbreaks experienced in 2007 and 2012 respectively as evidenced from Data Presentation 5.4.3.

5.3 Empowerment

In contrast to the concept of disempowerment that emerged from the participant's experiences around the outbreaks outlined above, the concept of empowerment or agency also emerged. Empowerment is defined by the Oxford dictionary as the process of becoming stronger and more confident especially in controlling one's life and in claiming one's rights. Empowerment occurs when individuals take matters into their own hands. An individual can become self-empowered after gaining confidence through experience where the individual is challenged to make decisions and follow one's conscience. Similar to a depressed state of tolerance, the ability to overcome adverse situations is innate.

Data Presentation 5.5
Theme 5: Empowerment

- | | | |
|-------|-------------------|---------------------------|
| (i) | Agency | (Data Presentation 5.5.1) |
| (ii) | Coping Mechanisms | (Data Presentation 5.5.2) |
| (iii) | Learned Mastery | (Data Presentation 5.5.3) |
-

5.3.1 Agency

In this study, self-empowerment was identified in a number of coping strategies employed by individuals and as a community. These included both internal and external coping mechanisms.

Data Presentation 5.5.1
Theme 5: Empowerment
Category 1: Agency

(i) Resilience	(Data Presentation 5.5.1.1)
(ii) Fluid Therapy and local interventions	(Data Presentation 5.5.1.2)
(ii) Duty to Patient Care	(Data Presentation 5.5.1.3)
(iii) Motivation	(Data Presentation 5.5.1.4)

5.3.1.1 Resilience

In the Bundibugyo case study, an interim period extending beyond five months was experienced. Despite requests for intervention, support was not forthcoming until following official announcement of EVD on the 29th November 2007. Some health care workers adapted to this situation without support.

Data Presentation 5.5.1.1
Theme 5: Empowerment
Category 1: Agency
Open Code 1: Resilience

- *On 30th of November, it was in the evening we saw a team of people, some were from World Health Organization, Ministry for Health, Médecins Sans Frontières and others. They found me in the place, the first thing they did was they gave me three pairs of gum boots and some gloves, some aprons and some gowns, and masks, face masks and caps [] they told me they have come to give us support (IDI, B5).*
- *Because we picked courage after working for one month without support from outside in terms of maybe Ministry, what I mean by outside, outside the district, expertise. We worked the same people as here who had little knowledge and we were trying to save people before we got to know what was the problem and now that they declared this was the problem I believe without even MSF coming or without Ministry as long as they were giving us facilities in terms of supplies we would have managed Ebola. (IDI, B6)*
- *So the cases that were coming to Kagadi, you would find that they were managed by very few people and most of them were nursing assistants but they tried at their level best at least for the first 2 weeks they were receiving those people (IDI, B2).*
- *I don't know what kept me strong, but the thing is, this disease [], once you stop fever, diarrhoea, vomiting, those signs you can survive, from the time of abortion, for me I stopped, the fever stopped, the bleeding, the bleeding stopped, the vomiting stopped, even I was with sweating, diarrhoea, diarrhoea also stopped, then after there every day every night what they advised to drink, to eat but I was eating little, they tried to bring me balanced diet, I tried to balance the food, small small, small small with a lot of drinking Ah slowly slowly (IDI, K10)*
- *the rest of the cases were brought in here and we did the investigations which we could at this level until the end of the day we couldn't, another patient died, another patient died, then we took the*

samples to Kampala [] the laboratory for the Ministry of Health, then at the end of the day, they told us there was nothing detected, so we kept like this. We would treat symptomatically and patients died, until we lost our staff (IDI, K2)

The first excerpt demonstrates how a health care worker remained in the isolation ward where one by one each of his colleagues fell ill and died. He refers to the memory of the arrival of external intervention finding him alone in the isolation unit.

In the second excerpt, a participant conveys the willingness of the health care workers to manage the crisis even in the absence of support. His argument is that if given the basic resources, they had the capacity to adapt to the situation. Getting on with the duty of patient care and using whatever resources were available was a familiar concept in these contexts. This concept of ‘adaptation’ to adverse circumstances was also recognised in a similar phenomenological study of the EVD outbreak in Kibaale (Matua, 2014).

In both case studies, health workers initially reported how they treated the cases according to the presenting signs. Isolation precautions were also employed before official announcement due to their suspicions that they were dealing with a highly infectious disease. In Bundibugyo, a wooden structure for the isolation of cholera patients had been constructed by MSF in the 1990’s and was set up as a temporary isolation unit before the arrival of external intervention. Also, in Liberia communities used a number of innovative mechanisms at the micro-social level in the absence of resources for health and infrastructure (Abramowitz *et al.*, 2015).

5.3.1.2 Fluid therapy and local interventions

Data Presentation 5.5.1.2

Theme 5: Empowerment

Category 1: Agency

Open Code 2: Fluid therapy and local interventions

- *Ah he come in the ward, he find me when I’m on the floor, I cant manage, I cant help myself [] he tries to give me the water [] the thing which helps me was drinking, drinking eagerly [] when they enter in the room I say you give me water, they give their water, If I managed to carry the bottle of water. I take I take, I take, I was taking a lot, a lot of water (IDI, K10)*
- *Mulago, so I communicated to him how I was feeling, he told me “that one is Ebola but what you do is you make sure you are hydrated”. So that time I was still able and someone assisted on how to put in a cannula, in isolation [] I could keep 5 litres of ORS (oral rehydration solution) during the day and night I was constantly drinking (IDI, B8)*

- *The treatment, we actually depended on orals [] they also put there some kamazi? [IV fluids] you would get it and put it in water and then the water boils as if it is on a stove (makes noise) that one I also think helped us (IDI, B12)*
- *Because here we were not doing much, just giving supportive care, dehydration, antibiotics and what not, was really all, and it was working, because we even recovered a pregnant lady [] she aborted and I was the one who evacuated her and she survived [] I think we gave her blood also, transfused her with blood (IDI, K1)*
- *With Ebola we saw that one of the things that was causing the death of patients was dehydration, at least if it happens again we would make sure that we would use the methods that we used that time and at least the death rate won't be like it was that time, that's is what I just hope (IDI, B5).*

5.3.1.3 Duty to patient care

According the Royal College of Nursing in the UK a 'duty of care' in the medical profession refers to legal and professional obligations placed on health practitioners to act towards others they have assumed responsibility for. In legal terms, the law imposes a 'duty of care' on health care practitioners in situations where it is reasonably feasible that the patient might be harmed through their actions or omissions (RCN, 2016). Failures in the duty of care have been identified in situations where staff experienced an unsafe workload, unsafe environment or taking on duties that they were not trained or competent in. In both case studies health workers continued to care for their patients despite working in an environment where they exposed themselves to a life threatening infectious agent with a lack of basic protective resources and external support.

Data Presentation 5.5.1.3
Theme 5: Empowerment
Category 1: Agency
Open Code 3: Duty to Patient Care

- *Most of them fled the hospital, then remained just a few of us, then the one who was in charge of the nurses, the senior nursing officer in charge of the hospital she died [] it is indescribable because it came to a time when I would work 24 hours (IDI, B5)*
- *when people ran away, there were courage, health workers here like a senior clinical [] he came out here, went to treat those people. I escorted him, he had protective gears and we put on our gum boots, we went there inside, to give the treatment (IDI, K4)*
- *Actually currently it (the risk allowance) is not enough, except that you have to adhere to the ethics because whether little, whether lot you have committed yourself that you have to serve the people, so diligently even if it is not there, you would have to save the lives because it would look unethical for people to die when you are actually looking at their lives and moreover you are the person who committed yourself that you will serve these people under whatever circumstances (IDI, B8)*
- *Actually you can ask yourself why in-charges, in-charges, because the staff abandoned work in the hospital and now as a rule in government that if your subordinates stop work, you as an in-charge are supposed to take responsibility, so when other staff ran away the in-charges by mandate were*

supposed to remain and take in charge, that's why you find all those people who died were at the position of in-charge, nursing officer in-charge, clinical officer in-charge, ophthalmic clinical officer, medical officer also these were all in-charges of departments (IDI, B6)

- *I voluntarily accepted after seeing there was need because everyone was fearing, because according to the information they were given they said actually the body in the highly infectious part of it, so people never wanted to work there, I said fine, since it is related to my office, I can handle it (IDI, K3)*
-

The first excerpt refers to the decision taken by some of the health workers to remain and manage the situation conveying a sense of resilience and agency. After many hospital staff had fled, they took control of the situation and implemented infection control procedures with the basic resources they had before external intervention arrived. Their motivation to remain even before allowances were given was based on a sense of ethics and duty to their patients.

In the fourth excerpt a participant explains why it was mostly senior staff (*in-charges*) that died during the Bundibugyo outbreak as they were duty bound to their responsibilities to the patients under all circumstances. The finding of an exceptional commitment to the duty of patient care found in this study are similar to findings from anthropological studies done by Hewlett and Hewlett (2005) during Ebola outbreaks in DRC (1995), Uganda (2000-2001) and the Republic of Congo in 2003.

5.3.1.4 Motivation

According to the Oxford English dictionary the term motivation refers to the act or process of giving someone a reason for doing something. Deriving from the word 'motive' meaning need wants or drive within the individual.

Data Presentation 5.5.1.4
Theme 5: Empowerment
Category 1: Agency
Open Code 4: Motivation

- *But after seeing "Ah she has come, he has come" they also started coming. Now what brought most of the staff back was the one who gave them some motivation, when the money came they started giving the allowances and they also came because now the situation had improved at that particular time because some little money to look for food for the patients and we were feeding the entire staff from here (IDI, K2)*
- *What motivated me was the nature of my training, when I went to Mulago National Referral for the training, that, how to handle that office we were given some skills of how to handle the body because we believe that any body is infectious so you should reach maximum precaution to handle them (IDI, K2)*

- *But the first motivation was actually the conscious that we have a problem and its ours and we have to do something about it but we are lucky we have taken consistence from WHO, taken consistence from the Ministry of Health, from MSF and we are working together so basically that's is (IDI, K7)*
 - *Some willingly came in, others came in because they heard there was some allowance, risk allowance and some came in because with the risk allowance in addition to assurance that you were really protected (IDI, K11)*
 - *It was so motivating because in spite of that problem that had claimed peoples lives, people had come together and people were going in, then you would just say if people can go in and go and face the patients, who are infected and from whom they can contract the, why can't we join hands and fight the outbreak (IDI, K11)*
-

5.3.2 Coping Mechanisms

Adapting to or dealing effectively with difficult situations usually involves employing certain coping measures. Coping mechanisms and self-preservation emerged as a category from within both outbreaks. According to Donnellan *et al.* (2006) coping measures are generally used to assess the mediating behaviour between a stressor (in this case a fatal disease) and the physical and psychological outcome of the individual. Every incident that includes a social adaptation between a person and the environment is appraised cognitively to its significance. These coping measures are therefore behavioural or cognitive responses directed at changing the emotional stressor or trying to avoid it (Billings & Moos, 1980).

A number of coping mechanisms were identified from the study and included both internal responses such as psychological, spiritual or emotional responses and external responses where individuals fled the scene of danger, or choose to manage the situation through problem solving, personal control efforts and optimism. A decision to move out of the health facilities or not enter them in the first place may reflect a rational decision process to cope with the situation, not necessarily always as a reactive response to fear.

Data Presentation 5.5.2
Theme 5: Empowerment
Category 2: Coping Mechanisms

(i) Protecting others	(Data Presentation 5.5.2.1)
(ii) Self-preservation	(Data Presentation 5.5.2.2)
(iii) Faith	(Data presentation 5.5.2.3)

5.3.2.1 Protecting others

In contrast to victims of EVD experiencing disempowerment, either as forgotten members in the community or patients contained and neglected within the health services there were many incidents captured where health care workers actually sought sanctuary within the health services where they worked.

Data Presentation 5.5.2.1
Theme 5: Empowerment
Category 2: Coping Mechanisms
Open Code 1: Protecting Others

- *So for me for my case my parents refused to bring me to Bundibugyo because deaths in Bundibugyo were rampant, the management in Bundibugyo was not so strong like the management we had in Kikyo, so those people were dying at morer rate than here, so my parents said no we shall not bring our [son] to Bundibugyo (IDI, B1)*
 - *When I woke up and my child had diarrhoea from there I said no it is too late to go even if I go and the child is already sick because for me I work, my wife is also a midwife, both of us work in the hospital, so we have got the disease and brought it home and now the child is infected so if we run away it is worse than for us to remain here and face it here, so that factor made me remain (IDI, B6)*
 - *So why I stayed, because when Ebola took place in Bundibugyo, many people died and me I felt if I ran away I am going to infect other people because I even received calls from my family members, the father of my children also called, he said please can you come? “You people I am not coming because I am already in an infected area, how do I know that I am safe, I could come there and infect people, let me die here alone so that I don’t infect others” (IDI, K8)*
 - *I wouldn’t feel like going home because I had to continue with the situation there, because I felt if I could go home I could take the infection home so I had to keep on (IDI, B10)*
 - *I remained, because I remember I was among the first people, because when I thought I should run, I feel I might spread that Ebola to my family (IDI, K4)*
-

The first excerpt conveys how the family of a health care worker had more confidence in the health facility where he worked rather than transferring their son to a larger hospital. Several excerpts convey how participants remained within the compound of the hospital to avoid transmitting the disease to their family members.

5.3.2.2 Self preservation

Some health care workers made a preferential choice to remain within their health facility than to move outside it. Several references were made to how some health care workers took control over their own treatment.

Data Presentation 5.5.2.2
Theme 5: Empowerment
Category 2: Coping Mechanisms
Open Code 2: Self preservation

- *I had a friend who is a doctor in Mulago, so I communicated to him how I was feeling, he told me “that one is Ebola but what you do is you make sure you are hydrated”. So that time I was still able and someone assisted on how to put in a cannula, in isolation (IDI, B8)*
- *I was suspicious right from the beginning up to the end. Whenever I was called for a patient, patient so and so has been, the condition has been getting worse I wouldn't rush, even before, even before MSF came in, I wouldn't rush to attend to the patient I would first think of my life (IDI, B5)*
- *Actually his death in Mulago, it was not that (the disease), because they failed (to treat him) [] they were just protecting (themselves), don't go what? it was like an office security threat.... (IDI, B5)*
- *I use the relatives of this person to take their body, I only open for them “ you keep it there” such that when I come back, I go and I wash my hands, I disinfect myself, then that's when I will go and do another duty because my consciousness' remains I'm still suspicious (IDI, K3)*
- *it is better to stay in a place where there is Ebola patients than staying in a community because here in this collection centres of Ebola patients, you know that I am dealing with a confirmed what?cases*
- *[] but outside the community you don't know the people you are dealing with, maybe maybe you may be travelling in public vehicles, seated with somebody with signs and symptoms, because it takes like 21 days to realise that somebody is? Affected, is sick- [] so you find he is even carrying on boda bodas, you may even get contact but when you are inside the hospital you know that they have brought a suspect, so you handle that suspect with a lot of care, so you are much protected than those ones who are there unknowingly (IDI, K4)*

In contrast to a sense of public duty, a more individualistic perception also emerged. Some health workers remained within their health unit, as they perceived it as a means of self-protection. They felt that the health facility was probably the safest option if they themselves became infected.

5.3.2.3 Faith

A common internal coping response that emerged most frequently among those who had survived the disease was faith and a sense of spiritual guidance.

Data Presentation 5.5.2.3

Theme 5: Empowerment
Category 2: Coping Mechanisms
Open Code 3: Faith

- *It is God who decided that I should not die, yeah, its God who decided (IDI, B5)*
 - *I believe it was God and that medication that saved me (IDI, B8)*
 - *Of course, you know I'm a Muslim and I took some very good time without praying, so after being discharged then I realised no, I have to thank God by praising him [] I go and praise God for what he passed me through, that was one experience (IDI, B12)*
 - *Automatically my wife was coming [to care for him in the hospital] then eventually she also had the disease, my young ones, just in my household nine of them were affected. ... But we all survived by Gods mercy (IDI, B2)*
 - *And I thank God because the sense which I remained, I was not expecting to be there (IDI, K10)*
-

In the third excerpt despite the trauma experienced by this participant as a result of becoming infected with EVD, the fear, stigma, and isolation by the community, the desertion by his wife and children he conveys an appreciation for God and the people who cared about him when he was ill. According to Manning-Walshe (2005), surviving a life threatening or traumatic event can often lead to a deep reflection and an expression of spiritual and existential issues to make sense of the experience.

5.3.2.4 Compassion

The theme of compassion was also identified from the analysis as part of the human experience in both case studies.

Data Presentation 5.5.2.4
Theme 5: Empowerment
Category 2: Coping Mechanisms
Open Code 4: Compassion

- *Then they stop her (him), "don't go there. Let the woman die alone, you don't go there [] then at least you can stay and you look for your children and when you go there and die with her, what are you going to benefit from there, you leave her" but one day he said "no let me go"[] Ah he come in the ward, he find me when I'm on the floor, I can't manage, I can't help myself to remove there the bottle of water and drink, he tries to give me the water, to pull me this direct, to try me and sit, I failed, he give me and I drink, by that time, but the thing which helps me was drinking, drinking eagerly (IDI, K4).*
- *They would say "mammy couldn't you go and help those people". Here that time (2012) we (Ugandan's) went to Ebola and helped people. I said "you my children, don't you fear that I can die from there?" They said "no mammy you cannot die, for us we are old enough, we can care about ourselves." I said now these children are courageous (IDI, K8)*

- *He was just a kind of a personal friend, so when he fell sick I went to sample him, I went to sample the blood from him and I did some tests on him and he was staying alone, he had no wife, he had no child he was staying alone in his house and of course you remember health workers had abandoned work and nobody was available to treat him [] he fell sick with the same symptoms and he was in his house and nobody was available to attend to him but for me as a personal friend I felt now even everybody has abandoned the doctor, for me I can not, I would rather die with him, so for me I went to attend to him (IDI, B6)*
 - *You come up and understand that so and so loves me because my phone was always on [] Gave me courage, encouraging words, if not then you ask yourself “where am I, do I have people who matter? (IDI, B9).*
 - *My wife would just stay with me and my mum and my dad would just touching me (IDI, B1)*
-

The first excerpt refers to the attempts of one victim’s husband to visit his wife in the isolation unit, and describes how he was discouraged. However, he persisted and contributed to her recovery by providing her with fluids. His courage and persistence to intervene in his wife’s recovery conveys his responsibility and love for her as her husband. In the second excerpt, a nurse describes the selflessness of her children as they encouraged her to go to West Africa and treat patients. In the third excerpt, another health care worker describes how he remained to take care of his colleague who was alone treating himself in his staff quarters. The fourth excerpt refers to a patient infected with EVD and how he retained hope through those who cared about him during his time in the isolation ward. In the final excerpt a health workers who became infected makes reference to the love of his family during his sickness.

5.3.2.5 Social Cohesion

A strong sense of social cohesion between the health care workers who remained to manage the situation when others had abandoned also emerged.

Data Presentation 5.5.2.5
Theme 5: Empowerment
Category 2: Coping Mechanisms
Open Code 5: Social Cohesion

- *We were together with other staff “down” – the senior nursing officer and clinical officer “we were all together”, cholera unit was full, we used part of the ante-natal clinic, “because every day people were coming”, new cases (IDI, B5)*
- *Me, it was me who got sick first then late X was attending to me, then he also got infected, then Y attended to late X he also got affected, and for late Johnson we had referred him to Bundibugyo hospital so he died from Bundibugyo Hospital (IDI, B2)*

- *What was encouraging us was when a health worker dies we even get more courage to work because when you see your friend die you say no, I'd rather work and save the other one, if I die that one will save the other one. Now that is what was motivating us to work, there was nothing like money no (IDI, B6)*
- *At first they even used to fear but as time came we reassured them “ please we are nurses who have come to care for you don't get scared” [] You would first see a patient who is not in mood of giving information but then we say “we are people like you but because of the dangerous disease we are hearing from which you are suffering from, that's why we are putting on this like this, so we are people, we are the nurses”, so than they were comfortable with us in time (IDI, K8)*

5.3.3 Learned Mastery

Data Presentation 5.5.3
Theme 5: Empowerment
Category 3: Learned Mastery

(i) Universal Precautions	(Data Presentation 5.5.3.1)
(ii) Increased Local Capacity	(Data Presentation 5.5.3.2)
(iii) Self-confidence	(Data Presentation 5.5.3.3)

5.3.3.1 Universal precautions

A shared theme that emerged was a reference to the importance of implementing the basics of infection control. The importance of water and sanitation, hand washing, clinical waste disposal and the availability of basic consumables to implement infection control such as having protective clothing and disinfectant in stock were the most commonly cited messages. In what one senior nurse referred to as reapplying ‘universal precautions’.

Data Presentation 5.5.3.1
Theme 5: Empowerment
Category 3: Learned Mastery
Open Code 1: Universal Precautions

- *We should do the ordinary things properly, we should have good sanitation [] in this hospital that one should be key, there should be adequate running water, the sanitation facilities especially the toilets and the bathrooms should have water and we should be able to clean them [] to me hand washing is the most essential really, emphasise on that always have soap and clean water at least for the staff and then for the attendants, an epidemic wouldn't take us by surprise [IDI, K1]*
- *We should be prepared for any eventuality, yes. You cannot disregard anything because it is those those, small small things that can make people get even contract infection or what [] like I already mentioned the universal precautions, if anything no patient should be handled without gloves [] It does not exclude people getting infected when you get an outbreak, but at least that would be the beginning (IDI, K11)*
- *One of the biggest lessons we have learned, so if it is unusual sickness, we must take serious precaution, if you take chances it may end up claiming your life, the moment the patient comes and*

presents with unusual signs, we should take serious precaution because many times through experience we have seen they take things for granted, for example you go and examine a patient with the bear hand, you have not put on gloves. Then coupled with that also the cleanliness should be up to date, if the cleanliness is not up to date [] still we shall have that challenge.

(IDI, K3)

- *Ebola it can be managed but when it is still early to stop..to stop from being spread from many people, so it needs early response, before it is spread to many people, thats all and even hand washing, this every 20 minutes to be washing hands like that, thats how Ebola can be managed (IDI, K4)*
 - *What I learned, that we should always be prepared and we should know how to protect ourselves, especially after handling every procedure, we must wash the hands with soap and water, most important (IDI, K8)*
-

5.3.3.2 Increased capacity

The experience of the outbreaks in both case studies also resulted in new knowledge among the participants. Lessons learned from outbreaks are more commonly heard from global health ‘experts’ who critique the outcomes in relation to policy and response decisions. In this study, the participants were asked what they learned from their experience with the outbreaks and a number of responses emerged.

Data Presentation 5.5.3.2
Theme 5: Empowerment
Category 3: Learned Mastery
Open Code 2: Increased Capacity

- *You know I later realised, people generally they get organised when an event strikes and you may not easily measure the capacity when there is no event [] Now having gone through the experience, I believe the health workers in Kibaale are more exposed than in other districts where such epidemic has not occurred (IDI, K7)*
 - *So I would instruct them I would be number one, because if there is any need where I have to take off some samples I am the one to do it because I am trained enough I didn't want them to meet problems so I will tell them to stand aside and see what I am going to do, to observe (IDI, K3)*
 - *We have, personnel that one I'm sure [] we sent our team to Kabaale they worked on it, on those patients and they came back safely, we sent them to Luwero, when there was an outbreak in Luwero and they came back nicely (IDI, K2)*
 - *Those who were already, who had already been to Gulu and they would just tell us “in case its this one, you do this” so we kept on learning even from those people who had an outbreak (IDI, K6)*
 - *The first thing I learned was that one, you should never underrate any condition, bearing that there are many diseases that arrive into Africa, any unknown diseases can come in any time and at all times you should always exercise safety precaution when handling any patient weather with a normal disease or with any strange disease (IDI, B8).*
-

5.3.3.3 Self-confidence

Having survived the experience, the participants emerged more confident including the health workers who experienced managing the outbreak and those that became infected and took control over their own treatment. These health workers conveyed a raised sense of confidence to cope with future outbreaks.

Data Presentation 5.5.3.3
Theme 5: Empowerment
Category 3: Learned Mastery
Open Code 3: Self-Confidence

- *If there is an outbreak now, we know how we can handle, at least we have got the basic knowledge about an outbreak what we are supposed to do, at least we know though some of the things to use may not be available as such (IDI, B2)*
 - *For us we are important, but it is very easy there at those other places to get people with a lot of sharing and communication. They can come out like we are but to get people who have cared for the patients and have the experience, that one also takes time []... I think that is most important (IDI, K11).*
 - *After declaring Ebola I believe without even MSF coming we would have managed, because we picked courage after working for one month without support from outside in terms of maybe Ministry, what I mean by outside, outside the district, expertise (IDI, B6).*
 - *Because when you are behind these mountains you think you are doing well when you are really doing nothing [] if you keep quite that means you are ok (IDI, B6)*
 - *I think now being through the experience like a woman giving birth for the first time (IDI, B6)*
-

A realisation that their experience has value was also expressed. Referring to a desire to participate in the West African outbreak, a respondent conveys why they feel that their experience with treating Ebola infected patients is an exclusive skill for contributing towards training other health care workers.

From the experience, a sense of self-expression and a desire to be heard was also identified among the participants who had managed the outbreak. The narratives convey a consciousness of how their voices are hidden under more dominant structural forces.

5.4 Chapter Summary

This chapter focused on findings that emerged from the local voices of Bundibugyo and Kibaale that have seldom appeared in the scientific or popular literature. A sensationalist narrative in the western media sensationalized EVD, leading to the expectation that

haemorrhage was a definitive symptomatic feature of case presentation. This resulted in misdiagnosis and delayed diagnosis, which resulted in the continued exposure of health workers to the virus and their subsequent death in many cases. This lies in direct contrast to the behavior blame narrative outlined in chapter 4 where delayed diagnosis was blamed on affected communities for failing to present at health facilities, seeking traditional medicines based on beliefs. Exoticisation of EVD and a dominant narrative that ‘no cure’ was available to treat EVD based on the assumption that only a drug or vaccine could treat a patient. This resulted in fear and avoidance by health workers to intervene, a term referred to as ‘therapeutic nihilism’. Similar to previous outbreaks, this resulted in mass abandonment by health workers and patients from health facilities and fear of the community to access health services. Patients found themselves contained in isolation units and denied health interventions and basic needs, instilling mistrust in the health system. Fear of confinement and mistrust in health officials was one of the major contributing factors towards the amplification of the outbreak in West African for example (Heyman *et al.*, 2015).

Official declaration of EVD brought a temporary importation of western interventions where all the resources required to contain and manage the outbreaks were made available and health units functioned efficiently. Health workers within these contexts perceived this situation as exceptional. Having achieved containment, management and observing no new cases after a 42-day period the outbreaks were officially declared over. From then an active normalisation process followed and everything returned to how it was found before the EVD outbreaks. This is what was observed at the time of data collection seven and two years following the outbreaks respectively. The health facilities in Bundibugyo and Kibaale had reverted back to the pre-EVD state of non-preparedness where lack of basic resources, functioning systems or budgets were in place to respond to a future outbreak or for the existing burden of endemic diseases.

In contrast to the consequences of exceptionalising EVD, empowerment in terms of local agency to manage the outbreaks before external intervention was captured among local experiences. Also captured were the themes of coping mechanism and learned mastery despite insufficient resources being available for infection control, patient care and self-protection.

Chapter six discusses themes that emerged from the findings and using several theories attempts to explore the subordination of local knowledge to dominant global narratives that surround EVD and other epidemics in global health.

Chapter 6 Discussion

6.1 Introduction

In this chapter, the five main themes that emerged from the findings are explored in relation to the concepts outlined in the literature review. Whilst some of the findings shared similarities with existing knowledge there were, several differences and disparities identified between the understandings, perspectives, and practical realities of those who lived through EVD outbreaks from those who inform policy to respond. The lived experiences and local understandings around EVD outbreaks in western Uganda are referred to in this chapter as ‘hidden narratives’ because they represent knowledge that is normally subordinated to global perspectives. These hidden narratives help to address the current knowledge imbalance by demonstrating the social and political realities in western Uganda, the historical power relations between the global North and South and the struggle of human identity. As outlined in chapter three the Medicoscapes concept was employed using the metaphor ‘landscape’ to frame the discussion to include the various dynamics and linkages of EVD as a global disease within one conversation. This chapter is divided into five main sections that embrace all five themes that emerged from the findings:

- A Behaviour Blame Narrative
- Structural Determinants of Delayed Diagnosis and Noscomial Transmission
- Social Realities of EVD Outbreaks in Western Uganda
- Consequences of Exceptionalisation
- Empowerment in Western Uganda

6.2 A Behaviour Blame Narrative

An attempt to deconstruct the ‘behaviour blame narrative’ that emerged as one of the main themes from the analysis serves as a point of departure for the discussion of the findings. Understanding how blame is assigned to individual behaviours and beliefs contributed towards addressing the second study question, to understand EVD outbreaks from local, national, and global perspectives in Bundibugyo and Kibaale in 2007 and 2012. From an

anthropological perspective, blame describes how individuals are held responsible for adverse health outcomes through their own actions or beliefs and this is sometimes referred to as a ‘behaviour blame narrative’ (Figure 6.1). This is not a new phenomenon as victims of infectious diseases are frequently blamed by governments, the academic community and the general public for their misfortune as a result of exposing themselves to risk factors of disease. A recent example is the case of Pauline Cafferkey a nurse from Scotland who contracted Ebola having volunteered in Sierra Leone in December 2014. Following her recovery she and her colleague were faced with disciplinary charges over allegations that they had concealed a temperature reading during a screening exercise at Heathrow airport. In one media report the nurse expressed disappointment with *Public Health England* that complaints made against her and her colleague who had risked their lives for the benefit of others were subjected to a ‘blame culture’ and failed to take responsibility for their own failing in the events that occurred (O’Carroll, (2016); *The Guardian*). Farmer (2005) refers to how individuals are blamed for the spread of MDR-TB, particularly those from within impoverished settings as ‘a new war on the poor’.

In chapter two (Section 2.5.3) an anthropological perspective was given to how humans understand misfortune by assigning a fixed range of possible causes and among these a plausible explanation is chosen that can result in action or inaction. It was outlined how communities and institutions tend to follow one of three dominant forms of explanation for a diseased state: to blame the individual (a moralistic view), to blame an enemy (an adversary) or to blame an external force (God or a spiritual entity) beyond the control of the individual. All three of these assertions emerged from the analysis in this study. The behaviour and beliefs of individuals in the EVD outbreaks in Bundibugyo and Kibaale study were perceived as a major determinant for the emergence, transmission and delayed intervention reported in both outbreaks by those furthest from the realities on the ground (Figure 6.1).



Fig. 6.1 Behaviour and beliefs as a determinant of EVD emergence, transmission, and delayed response in Bundibugyo and Kibaale

In this study the ‘behaviours’ perceived responsible for the emergence and magnification of EVD included hunting and eating bush meat, performing certain practices related to burials and seeking non-conventional health interventions [Data Presentation 4.1.1]. The participants in the study also conveyed how families and communities affected by EVD delayed to seek conventional health intervention and hence contributed to a delay in diagnosis and transmission of the virus because they believed that the illness and deaths they witnessed were a result of witchcraft or poisoning [Data Presentation 4.1.2.2; Data Presentation 4.1.2.3]. Some participants referred to a fatalistic view where a higher force beyond the control of those affected was believed to be behind the sudden illness and death affecting their families and communities and hence beyond health intervention [Data Presentation 4.1.2.4].

Although the data identified all three modes of blame surrounding both case studies supporting Douglas’ (1992) theory of human understandings of illness and blame, these perceptions were not analogous. Whilst the behaviour blame narrative was identified in the discourse of the community, at the national level and in the discourse of external bodies, a dichotomy existed between these three levels. For example perspectives of blame from those who experienced the disease ‘locally’ – the front line health workers, was different when compared with the perspectives of district health ministries and people located further from the outbreaks at the national and global levels. At the global level blame was culturally determined in what some authors refer to as a ‘cultural epidemiology’ (Leach & Dry, 2010). At the national and district levels blame was portrayed through ethnic and social stratifications where Congolese refugees, minority ethnic tribes and rural peasants were blamed for EVD emergence in both case studies [Data Presentation 4. 2.1.1]. Blame for EVD emergence was not directed at the community by any of the frontline health care workers in the study who managed the outbreaks despite the isolation and stigma they themselves experienced from the community during and following the epidemic. Frontline health workers conveyed a more rationale view of blame. Delays in diagnosis, response and containment of the outbreaks were blamed on the disempowerment of health workers within the system to make decisions [Data Presentation 4.2.1.4], lack of resources for epidemiological investigation and diagnosis by those who had the skills to respond [Data Presentation 4.2.2.3] and lack of resources within the health units to manage a response [Data Presentation 4.2.2.1]. Misdiagnosis was also blamed on the similarity of EVD to other endemic conditions where haemorrhagic features were absent. Haemorrhagic

features were perceived at the time of both outbreaks as a defining clinical sign for diagnosing ‘haemorrhagic virus’ [Data Presentation 5.4.2.1]. This knowledge was disseminated by international sources of health expertise.

Health workers blamed the death of their colleagues on the scarcity of resources to implement protective and infective measures within the health units during the outbreaks [Data Presentation 4.2.2.4]. Several social determinants underlying hunting and seeking alternative sources of health intervention also emerged among local perspectives [Data Presentation 4.3.1]. Specific to the Bundibugyo case study, the CHOGM event in 2007 emerged as a political determinant underlying the delayed response by government to the outbreak [Data Presentation 4.2.1.3].

The findings support a theoretical argument outlined in the literature review, when African culture is assigned as the main determining factor underlying EVD outbreaks it fails to consider any deconstruction of underlying structural forces. These findings can be described as ‘hidden narratives’ as they represent knowledge underlying EVD emergence and amplification that remains subordinated to a dominant behaviour blame narrative at the global level. This subordination of relevant knowledge represents a current knowledge imbalance between the global North and South in international health development.

6.2.1 Cultural Narratives and Colonial Ideology

The interdisciplinary field of research that considers the distribution of epidemics in a cultural context is referred to as a ‘cultural epidemiology’ (Weiss, 2001). In the literature review, chapter two (Section 2.5.2) the concept of *Cultural Theory* or a ‘cultural model of disease’ described how individuals and groups perceive disease based on the communities, institutions or nations from which they belong (Leach & Hewlett, 2010). An example was conveyed using one study that explored the meaning of EVD within the traditional belief system of the Acholi people of northern Uganda, where the largest recorded EVD outbreak in Uganda occurred between 2000 and 2001 (Hewlett & Amola, 2003). Leach and Hewlett (2010) posit that an interdisciplinary approach to understanding illness and disease within communities taken from anthropological as well as biomedical and epidemiological research can better inform policy for planning interventions during epidemics. They refer to this interdisciplinary approach as “*identifying valuable health enhancing local knowledge and cultural categories which can be blended productively with scientific*

knowledge". An argument against this view was also outlined in chapter two that critiqued an emphasis on African culture as a determinant of EVD emergence. The author claimed that this represented a racial expression embedded in colonial ideology that remains embedded in the popular and scientific language surrounding EVD (Jones, 2011).

In this study, culture was specifically referred to as a determinant of behaviour and beliefs that were understood to result in EVD emergence or a barrier to control efforts. In Data Presentation 4.1.1.2, for example all excerpts make specific reference to 'culture' when describing behaviour around the burial practices of whole communities affected by EVD. These references to culture were identified by those trained in the burial teams during the intervention phases of the outbreaks and from data sources external to the contexts of Bundibugyo and Kibaale [Data Presentation 4.1.1.2]. As mentioned above none of the frontline health workers at the hospitals or health centres assigned the term 'culture' as a determinant of EVD emergence in either of the case studies.

In another example a newspaper excerpt identified from the Kibaale case study in 2012 maintained that the family where the virus emerged in Kibaale had delayed accessing health services because they had initially sought assistance from a spiritual healer. On speaking directly with the surviving head of this family, she explained that they had admitted the first cases to a private hospital in Kagadi town, St. Ambrose. When she could no longer afford to pay for private treatment, she admitted subsequent family members who fell ill to the public hospital. Twelve of the family members died during the EVD outbreak and she was left with the burden of caring for her orphaned grandchildren in the aftermath. Her and her remaining family members remain stigmatised and isolated within their community two years following these events. She interprets her circumstances to being 'cursed' but the media article portrays her reference to being cursed as a backward and ignorant belief system [Data Presentation 4.1.2.2]. This was an example identified in this study how understandings of EVD outbreaks were influenced by non-evidenced based narratives.

Generalisations void of contextual understanding were also identified in this study [Data Presentation 4.1.1.1]. Whilst all of the excerpts convey a behaviour blame narrative, a WHO health expert makes a specific claim to knowledge about Ugandan culture as a determinant for EVD emergence in Kibaale in 2012:

"Ugandans are known to love bush meat".

A second excerpt from a global health expert conveys a similar generalisation:

“Typically in the Africa setting that’s [contact with Ebola virus] been with hunting or eating, marketplaces where, there I guess bush meat with monkey meat in it” (ABC, news 31st July 2012, DA)

In Data Presentation 4.1.1.2, another external observer makes a specific claim to knowledge of Ugandan culture with reference to the potential mode of virus transmission during a burial process:

“Many wept and caressed the corpse following Ugandan custom (CDC, 2012; DA)”.

With reference to the latter, there are over 65 constitutionally recognised ethnic groups and 6 major religions in Uganda who practice a variety of ‘burial rites’ and none can be described as typically ‘Ugandan’. Such simplifications are frequently used to formulate ‘global’ narratives of EVD outbreaks that appear in both the scientific and popular literature. Dash (2016) claims that cultural inaccuracies are generated through the use of homogenous concepts supporting a neo-colonial discourse that ignores the vast assemblage of African societies and civilisations and the mass of cultural diversity that exist even within individual countries. These generalisations portray ‘Africans’ as a homogenous group whose thoughts and actions are governed by culture and beyond individual rational thought. Wayland *et al.* (2002) argue how popular simplifications of community relationships create the impression that ‘the local’ is stagnant, illogical, and ignorant. Other terms frequently used to describe African contexts such as ‘development’ share similar racial forms of expression between the powerful and the oppressed nations, subtly implying that the people within poor regions are somehow less ‘developed’ than those in wealthier nations. In chapter two a reference from a group of western medics involved in emergency response during the West African EVD outbreak referring to the ‘attributes of the affected population’ as a barrier to control efforts was identified (Aylward *et al.*, 2014,p.1487).

In chapter two Jones (2011) critiqued an over emphasis on culture in Western mass media as a determinant of EVD emergence that displays an exaggerated and exoticised view of African society as backward and ignorant. Some of the media coverage surrounding both case studies in this research identified this exoticisation of EVD [Data Presentation 5.4.2.1].

Blood fills the intestines, the digestive tract, and the bladder, spilling out of the nose, eyes and mouth...and the corpse of a body remains ‘hot’ for days (Hammer, CDC, 2012)

Unfortunately in the absence of studies inclusive of local perspectives and empirical understandings of the contextual realities of EVD outbreaks it is such perspectives that comprise available ‘knowledge’ and repeatedly inform global understandings.

“History seems clear and undeniable because the analytical perspective has made it so [] leaving the psychological impression that one is experiencing reality-driven objectivity” (Bennett & Edelman, 1985: 162).

Dash (2016) argues how such cultural theories about African peoples reflect how the North perceives, understands, and knows the world. A ‘cultural epidemiology’ of EVD outbreaks conveys how a prevailing knowledge hierarchy of international development with ‘global’ (Northern) knowledge at the top and ‘local’ (Southern) knowledge at the bottom exists.

6.2.2 Cultural Hegemony

Whilst none of the frontline health workers or hospital management from Bundibugyo or Kibaale assigning culture as a determinant of EVD emergence, some perspectives from the national and regional levels were identified to portray a cultural epidemiology of African society [Data Presentation 4.1.1.1 and Data Presentation 4.1.2.1].

In Data Presentation 4.1.2.1, for example Congolese refugees are blamed for eating bush meat and therefore EVD emergence. In Data Presentation, 4.1.2.2 ‘people’ (rural communities) are blamed for believing that illness and death are related to witchcraft and therefore delayed seeking conventional medicine. In Data Presentation 4.1.2.3 explanations, that ‘certain tribes’ claim that other ‘tribes’ poisoned them was also portrayed as a belief that delayed investigations into the outbreak. These social stratifications include refugees, rural peasants, and minority ethnic tribes evidenced by the terms used to describe them during data collection. The common link between these groups is that they belong to what may be perceived as a lower class along the socio-economic scale in Uganda.

These views are expressed by the participants through a lens similar to the ‘cultural epidemiology’ outlined above. This reflects a ‘class epidemiology’ where those conveying their opinions present themselves as more knowledgeable or ‘superior’ to an inferior

group, portrayed as ignorant and backward. This may reflect a conscious or unconscious attempt to make a clear distinction between themselves (as rational humans) with ‘others’ to disown the identity generated by a dominant western narrative. In the study at the socio-economic class level of international ‘health experts’, culture is frequently assigned as the underlying determinant of blame. However, at the level between national and local or local and community, the ‘us’ and ‘them’ dichotomy is assigned to a ‘class epidemiology’.

The emergence of this class epidemiology could be a consequence of the expressions of racial hegemony portrayed as a dominant narrative in the global media. It may have created a divide in identity among Ugandans themselves in how they are perceived globally in terms of EVD emergence. By wanting not to disassociate from the stereotyped image of ‘primitive, local and ignorant (or inferior) they identify themselves with the ‘civilised international experts’. The following excerpt from the data portrays a desire to self-identify with the ‘superior’ or ‘expert’ group.

“I’ll attempt to co-ordinate with many of my friends who for example I acquired during that exercise of controlling Ebola and I also have some friends in USA. Because even these people from WHO know me personally...but I would wish to be an international public health worker” (IDI, B4)

Several terms used in this excerpt (“my friends”, “friends in USA”, “people from WHO know me” and “I would wish to be an international public health worker”) refer to a desire to self-identify with the ‘expert’ or ‘superior’ group, and therefore distinguishable from the ‘ignorant’ and ‘inferior’ groups. Later in the interview, the same participant expresses a strong behaviour blame narrative that portrays the community as ignorant, backward, and hence ‘inferior’.

“behaviour is playing a very big role because why I am saying this is because anywhere in Bundibugyo town here you will find open defaecation still taking place and I think that is a behaviour issue” (IDI, B4)

A desire to self-identify with global health ‘experts’ may also be influenced by the exceptionalisation that surrounds EVD. EVD outbreaks have come to be perceived as geopolitically important public health crises that capture international political attention. The dominant narratives and persistent images of Ebola response teams donned in PPE’s versus the stark contrast of the impoverished surroundings from where most outbreaks emerge feeds into a perception that EVD is an exceptional disease.

A desire to differentiate from a racialised image of ‘African society’ as ignorant and backward outlined above can be mitigated by formulating an opposing image and hence a divide in social identity. This may reflect a socio-psychology rooted in colonial

oppression, dictatorship and self-diminishment and supports Franz Fanon's social theory that racial forms of expression dehumanise people and generate a self-understanding by the oppressed that they are outside the scope of humanity and therefore inferior (Fanon, 1967). The findings from this study support this argument where Africans themselves maybe generating a self-understanding and shame towards their community who are conceptualised through a global racialised lens as being ignorant and backward. These feeling of shame seem to be further supported by the unwillingness to look bad in the eyes of visiting dignitaries [Data Presentation 4.2.1.3] that may represent a lingering colonial legacy. To counteract this label of inferiority either consciously or subconsciously an attempt to self-identify with the 'civilised' and hence 'superior' westerners is made.

It must also be considered that the study participants who made specific reference to culture were from 'health experts', public health representatives and members of the burial teams. All of these groups had received training in epidemiology and public health and were exposed to global perspectives and dominant narratives that commonly attribute blame with culture in EVD emergence. It can be argued that racial ideology is translated through a teaching curriculum influenced by global narratives under the direction of colonial and neo-colonial players far removed from the social realities of Bundibugyo and Kibaale.

The divide in social identity identified from the findings maybe a consequence of a 'cultural hegemony' that has surrounded EVD outbreaks for decades and mimics the social basis of colonial ideology used historically by missionaries and colonialists (Fanon, 1967).

Cultural hegemony refers to the concept that where culture as an ideology or a consciousness of what is perceived as right or wrong and becomes common sense for the majority of the population (Gramsci, 2000).

"Politics is not only fought in state houses, workplaces or on battlefields, but also in the language we use, the stories we tell, and the images we conjure – in short, in the ways we make sense of the world"

Cultural hegemony is dehumanising and de-politicising because it overlooks other forces that shape reality such as government policies or the larger structural determinants of poverty that also emerged from the findings in the study. According to Connell (2007) applying universality to knowledge functions as an ideology conditioning the way in which

decision makers view the world and the policies that they follow. This explains why policies are followed even when empirical evidence points to the contrary.

'The concept of 'universality' may represent the views of the most 600 million assuming that the same views are experienced by the whole 6000 million who are actually in the world' (Connell, 2007)

The theory of 'cultural hegemony' could explain the basis for creating a superior or elite group who embrace western views and concepts around EVD outbreaks. Adopting concepts such as 'universal consensus' and a 'global public good', as a perceived altruistic attempt to achieve 'global health security' was critiqued in chapter two (section 2.6.7).

6.3 Structural Determinants of Delayed Diagnosis and Nosocomial Transmission

While those assuming a behaviour blame narrative were far removed from the contextual realities on the ground, it might also be hypothesized that those on the ground are sometimes obscured from the larger structural forces that socially determine their vulnerabilities to disease emergence under a burden of everyday challenges. Analysis of the local voice recorded in this study resulted in the emergence of the second theme of the study, structural determinants of delayed diagnosis and nosocomial transmission [Data Presentation 4.2]. This theme emerged from a number of categories identified as some of the main social determinants underlying EVD emergence and amplification [Data Presentation 4.2.1].

6.3.1 Social Determinants of EVD Outbreaks in Bundibugyo and Kibaale

According to WHO, the social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at the local, national and global levels (WHO, 2016). The social determinants of health are mostly responsible for health inequalities – the unfair and avoidable differences in the health status for individuals within and between countries. Whilst the main aim of this study was not to identify how EVD emerged in Bundibugyo or Kibaale districts in 2007 and 2012, it was an objective of the study to arrive at a better

understanding of the contexts from which they emerged and amplified bearing in mind that social circumstances account for biomedical outcomes.

According to Orach, (2014)

“Health inequalities are the result of a complex system at the global, national and local levels which shapes the way society at national and local levels organises its affairs and embodies different forms of social positioning and hierarchy”

6.3.2 Institutional Hierarchies

Power imbalances are also identified in the exclusion of Africans from the ownership and control over the international organisations that inform international health policy. The behaviour blame narrative discussed above in section 6.2.1 identifies a North-South power imbalance in terms of knowledge ownership that informs ‘global’ health policy and influences responses to EVD outbreaks at the ‘local’ level. In the previous section imbalances between global and individual health security during EVD outbreaks were observed across a North –South divide.

Power dynamics were also identified at the national and local levels within the health systems between the MoH at national, district and hospital level and between the health unit levels. Data Presentation [4.2.1.2] demonstrates these institutional hierarchies where health workers have no control in the decision making process required to implement response to reports of deaths within the community including EVD outbreaks. Despite the levels of health service delivery outlined in Table 1.2 the system functions from top down, from central government to the national, district, hospital management and finally the level of the front line health workers. At the very bottom of this hierarchal structure are isolated and marginalised communities who have no power in the decision making process that impact their health outcomes [Data Presentation 4.2.1.1].

In both outbreaks the decision that triggered external support was based on the official announcement of laboratory-confirmed EVD and not by the fact that people were becoming ill and dying from an unknown infectious disease in western Uganda [Data Presentation 4.2.1.1]. From the findings delays in diagnosing the outbreak were blamed on the behaviour and beliefs of the communities affected even though the evidence shows otherwise (Presentation 4.1.2 versus Data Presentations 4.2 and 4.2).

A similar situation was experienced during the West African outbreak where delays in diagnosis were also blamed on several factors including human behaviour, the fact that West Africa had never experienced EVD before and because it presented similar to endemic diseases such as malaria and Lassa virus (Heymann *et al.*, 2015).

Responding to reports of multiple deaths from within impoverished communities in sub-Saharan Africa does not merit national or international attention because the cause might be 'endemic'. External support follows laboratory confirmed EVD and a decision to scale up international response relies on whether a particular EVD outbreak meets the 'criteria' of a PHEIC under the IHR. External response to the Bundibugyo outbreak was delayed by five months. In the Kibaale case study the delay was almost one month. As outlined in chapter two (Section 2.6.4) delays in declaring the West African outbreak a PHEIC arrived after 3000 probable, confirmed and suspect cases and over 1500 deaths among West Africans across four countries (WHO, 2014a). The final declaration to announce a PHEIC was influenced by the death of two North American citizens (Gostin & Friedman, 2015). The same eligibility criteria were used to declare Zika virus (a non-lethal pathogen) a PHEIC under the IHR in 2016. It was observed that the declaration of Zika virus as a PHEIC followed a shift in the geographic emergence of the disease from its origins in equatorial Africa to Asia, more recently emerging in four countries in South America. Its declaration as a PHEIC on the 7th February 2016 occurred following two confirmed cases that emerged in Texas, North America (Kindhauser *et al.*, 2016). Decisions concerning global health policies are still dominated by a small number of powerful actors from within the senior ranks of hierarchical government departments or international organizations dominated by powerful states.

Observing these events supports the argument that the development of surveillance and risk assessment strategies under an assumed universal consensus towards containing epidemics of international concern is an agenda to push protectionist policies aimed at keeping pathogens out of Western states (Davies, 2008). This is not a new phenomenon as history shows the six specific diseases included in the original IHR were those that threatened the socio-economic development of Europe and North America through the main shipping routes from south-east Asia (Evans, 1988).

Current interventions support the argument that lives lost within an African setting are perceived as less important than focusing on the containment of the virus. Health inequalities exist between and within regions and nations occurring along a socio-

economic, political, racial, ethnic and gender axis. For example in Australia there is a 20-year gap in life expectancy between Australian Aboriginal and Torres Strait Island peoples and average Australians. The former groups are socially excluded minorities within their country. Similar disparities in health are seen in the USA between the highest and lowest advantaged population groups (Murray *et al.*, 1998).

Since 1976 responses towards EVD outbreaks have not moved beyond a total dependency by the affected country on humanitarian type responses from the global community. The outcomes of EVD outbreaks for the individuals and communities most affected are largely determined by the strength of the health system to manage them. Yet little has been invested in long-term sustainable approaches that focus on health system strengthening or consideration for the social determinants that facilitate these outbreaks to emerge and magnify in the first place (Calain, 2007b). Scoones (2010) suggests current approaches need to become more inclusive of national realities where a wider spectrum of knowledge is brought to bear on complex problems. The emphasis on developing a sophisticated global surveillance network could be an inappropriate waste of resources and lost opportunities.

6.3.3 Weak Health System

The findings from this study identified how humanitarian interventions imported in to control the outbreak were locally perceived as an exceptional response not previously witnessed within the contexts of Bundibugyo or Kibaale health units [Data Presentation 5.4.1.1]. Once the outbreaks were controlled and no new cases identified within 42 days, a period equivalent to twice the incubation period, the MoH and WHO declared the outbreaks officially over. From here an active process of ‘unmaking the crises’ was identified in the Bundibugyo and Kibaale case studies [Data Presentation 5.4.1.5]. This process-involved withdrawal of the interventions imported in to contain the outbreak and reverting the health units in Bundibugyo and Kibaale back to ‘normal’. The term ‘normal’ here refers to the context within the health units prior to the arrival of external intervention [Data Presentation 5.4.1.1].

At the time of data collection the data captured during the interviews and observations [Data Presentation 5.4.3.1] found that the health systems had remained unchanged to the descriptions captured from the pre-EVD state of non-preparedness in 2007 and 2012 [Data

Presentation 4.2.2.1] that are non-compliant with the revised IHR (WHA, 2013) outlined in the literature (section 2.6.4).

The discourse in the role of weak health systems as an underlying determinant of EVD outbreaks mostly emerged into the scientific and popular literature following the West African outbreak (Boozery, Farmer & Jha, 2014; Gostin & Friedman, 2015). However since this unprecedented event practical measures supported through global health policy to prioritise health system strengthening have been slow to follow.

Dry (2010) argues how a preoccupation with ‘emerging infectious diseases’ has come to dominate global health policy in recent decades and has influenced a ‘homogenous set of approaches’ (Dry, 2010, p.30). These ‘homogenous set of approaches’ refer to reliance on rapid response in the form of humanitarian type strategies aimed at containment of outbreaks when and where they occur. Whilst this approach when applied to the Bundibugyo and Kibaale cases maybe perceived from a global perspective as having successful outcomes, it failed the communities, families and health workers affected. Reliance on rapid response strategies also failed over 11,300 West Africans between 2013 and 2016 (Larkan *et al.*, 2015).

High mortality experienced in African countries during EVD outbreaks is in part due to inadequate health systems and lack of resources. The findings from this study support this and that of most other EVD outbreaks where nosocomial infection and the loss of life were as a direct or indirect result of fragile health systems (Royo-Bordonada & García, 2016). Weak health systems are also a representation of the intrinsic inequalities underlying EVD outbreaks and their outcomes for most affected African countries, including Uganda.

Whilst the researcher acknowledges the highly infectious nature of EVD virus that demands urgent response and the rapid availability of resources, reliance on the current mode of response resembling a humanitarian intervention has several flaws. Global pandemic preparedness is justified but prioritisation of early warning systems for pandemic threats that may threaten international borders some day detract limited resources away from existing endemic realities that threaten the lives of the poor everyday [Data Presentation 4.2.2.6].

A counter argument for criticism of disease-focused interventions is that health system strengthening occurs as a public good from collective communicable disease control strategies (Smith *et al.*, 2004). It could be argued that there was an increased awareness of

disease outbreaks in the communities as a result of the hyper-vigilance surrounding the EVD outbreaks in western Uganda. Smith *et al.* (2004) identified significant limitations to the 'Global Public Good' concept. Vertical focused disease surveillance that may capture other communicable diseases is not necessarily an equitable form of health care delivery.

The findings from this study show that it was during the interim period prior to the official announcement of EVD that the majority of lives were lost including the lives of senior and experienced health workers. While the outcomes in terms of containing and managing the outbreak are perceived as successful, the health facilities were weaker in the aftermath as a result of a depleted team of human resources for health. Failure to take health systems strengthening as a serious focus in international health development will continue to result in the unnecessary loss of lives and further weakening of fragile health systems into the future. The strength of a country's public health system is largely determined by broader social and political factors that position affected individuals in situations where health outcomes are beyond their control.

6.4 Social Realities of Bundibugyo and Kibaale

Whilst poverty can be identified as an underlying determinant for EVD emergence, amplification and weak health systems to respond; poverty itself is the symptom of larger structural forces. Poverty as a social determinant of health cannot be addressed without considering the global forces that underlie it.

It is a foregone conclusion that the international slave trade, colonial rule and the subjugation of African peoples and resources throughout the continent served the structural violence that is there today. Chapter two (Section 2.3.3) referred to the global trade structures imposed on post-colonial sub-Saharan African economies designed to meet the demands of industrialised Europe through the export of cheap raw materials. This has remained largely unchanged since the colonial era with several new players on board in what is sometimes referred to as the 'second scramble for Africa' (Carmody, 2011).

Economic power relations can be identified in this study underlying poverty among the majority of the population in western Uganda who represent subsistence farmers depending on cash crops such as coffee, tea and cocoa competing with world market prices where Northern agricultural subsidies and a global decline in trade for primary commodities. Following on from section 6.3 this section continues to consider the social

determinants of EVD emergence and amplification by exploring the consequences of poverty and war that emerged from the findings.

6.4.1 Poverty as a Determinant of EVD Outbreaks in Western Uganda

Globally health follows a socio-economic spectrum with the poor having the worst health outcomes (WHO, 2017). Poor people in LIC's are more susceptible to illness and disability due to poverty and its associated features of food insecurity, unclean water and lack of sanitation, overcrowding, polluted environments and inequitable access to healthcare. It is therefore not an enigma that these multidimensional features of poverty including food insecurity, limited income, access to healthcare, living conditions and endemic burden of disease emerged from the data [Data presentation 4.1.1].

A large proportion of the scientific literature reviewed in chapter two refers to the virus from a biological and epidemiological perspective. These accounts depict the virus emerging among primitive villagers in contact with wildlife in isolated pockets of tropical rainforests across equatorial Africa and less attention is given to other social features that portray a broader understanding of these contexts. Leach and Dry (2010) consider how central African forests from where 'novel' viruses 'emerge' are not virgin ecosystems undergoing new disturbance but have been shaped by interacting and non-linear anthropogenic and climatic influences over centuries and millennia. This theory is supported by more recent studies on genetic diversity that suggest Ebola virus species date back 750 to 800 years (Carroll *et al.*, 2013). This justifies enquiry beyond an epidemiological explanation between a pathogen and its host towards a broader perspective to exploring EVD emergence by taking the socio-ecological factors outlined into consideration and by asking what has changed.

The populations in Bundibugyo and Kibaale have increased exponentially over the last decade with a subsequent demand for agricultural land and food sources (*Higher Level Government Statistical Abstract: Bundibugyo District, 2009; Higher Level Government Statistical Abstract: Kibaale District, 2009*). In Bundibugyo the landscape is hilly and susceptible to soil erosion and landslides. The low-lying flatlands are prone to flooding and overgrazing. About 59% of the land in the district is gazetted to wildlife parks creating pressure on remaining agricultural land. Competition in sourcing food and livelihoods underlies why poor communities in Bundibugyo and Kibaale are more likely to encroach

wildlife habitats and risk contact with zoonotic sources of infection or a contaminant in the environment [data presentation 4.1.1.1].

The ‘cultural epidemiology’ outlined in section one as a stand-alone explanation for EVD emergence, transmission and delayed response has limitations because it obscures other important factors in its emergence such as the social determinants that influence the available choices that frequently underlie human behaviour. Referring to the Kibaale outbreak in 2012 several members from the family died in both private and public institutions as a result of not being diagnosed or treated adequately for EVD [Data Presentation 4.3.1.3]. While public health services in Uganda are free, informal fees are frequently charged and access to treatment in an already overburdened system is challenging (UBOS, 2004). Therefore the general public perceives private clinics and hospitals as equivalent or superior to public health institutions.

Burial practices blamed as a cultural epidemiology of EVD transmission also have a social dimension [Data Presentation 4.1.3.1]. Whilst it is traditional practice among most groups that a deceased family member is buried on the land of their ancestry this practice also reflects a practical and cost effective means of managing the dead, particularly among the rural poor.

During epidemics attention is rarely drawn towards the structural causes of infectious disease but instead an emphasis on behaviour blame narratives of disease causation described in section 6.2.1 above prevails (Wald, 2008). In this study several social determinants were identified that have previously been subordinated to a cultural epidemiology reflecting the local voice that is commonly absent from the narrative [Data Presentation 4.3.1].

6.4.2 War as a Determinant of EVD Outbreaks in Western Uganda

The influx of refugees into western Uganda is not just a causality of an isolated ‘conflict’ occurring in a country neighbouring its border. The Ugandan (and Rwandan) governments and their external allies provide military support and a global markets for commodities extrapolated from eastern DRC. All are lead players in the structural determinants underlying why thousands of refugees are forced to flee eastern DRC into overcrowded slums and settlements where they become vulnerable to infectious disease outbreaks including EVD.

All Ebola outbreaks to date have emerged from within impoverished communities with non-existent or rudimentary health systems and in many cases from countries that have experienced recent wars and conflict. There have been five recorded EVD outbreaks in Central DRC between the period 1995 and 2014. During this same period five cases of EVD have also been recorded in Uganda (Chapter 1, Table 1.3). Whilst most of these outbreaks occurred outside of the 'official' dates of the first and second Congo wars from 1997 to 2002, on-going conflict, violence and human displacement continue to be experienced in eastern DRC even up to the time of writing. According to Ghobarah, Huth and Russet (2003), the long-term burden of disease and disability caused by war far outweighs the number of deaths during fighting. The occurrence of EVD outbreaks during the period of the Congo wars cannot be ruled out since the destruction of health systems and displacement of human resources for health would have removed any capacity for EVD epidemics to be identified or recorded. According to Bompangue D. *et al.* (2009) no research had been conducted to identify sources of epidemics throughout the North and South Kivu provinces in eastern DRC prior to 2000.

In chapter two (Section 2.3.4) Chrétien (2006) argues that colonial partition in the Great Lakes region divided the literature on political history into French-Belgian and English strands as if referring to two separate regions (Chrétien (2006, p.9). Decades of wars and conflict affecting the region have resulted in human and animal displacement, the disruption to livelihoods, food insecurity, and abject poverty. Just as the political history of eastern DRC and western Uganda cannot be separated, neither should the social and structural determinants underlying the epidemiology of disease emergence.

Prior to the civil war in South Sudan in 2015, Congolese refugees represented over 65% of the total refugee population in Uganda (UNHCR, 2013). For example in 2012, 45,854 refugees were newly registered in Uganda originating from eastern DRC (UNHCR, 2014). Bundibugyo and to a lesser extent Kibaale have experienced the effects of these displaced populations both directly and indirectly. Living conditions experienced by the displaced Congolese seeking refuge in the camps and informal settlements comprise overcrowded spaces with lack of adequate food, water and sanitation services that inevitably result in infectious disease emergence [Data Presentations 4.1.1.4 and 4.1.2.2]. These images are similar to those that allowed cholera and other infectious diseases to flourish during nineteenth century industrialisation in Europe and North America.

McPake *et al.* (2015) state how conflict and war results in the displacement of large numbers of people away from their land based subsistence livelihoods forcing them into marginal enterprises such as hunting, fishing and forest-based enterprise. In addition to the risks for civilians, the combatants are also forced to seek out a survival through hunting and poaching from the environment in which they find themselves advancing or retreating. In Uganda's first EVD outbreak in Gulu, northern Uganda between 2000 and 2001, the Acholi population blamed the transfer of military personnel returning from the DRC to bases in Gulu as the origin of the outbreak (Hewlett, 2001).

Several references are made in the data to cholera, dysentery and typhoid outbreaks witnessed in the camps and informal settlements near the lakes in Bundibugyo and Kibaale [data presentation 4.1.1.4; 4.1.1.5]. These findings are akin with the findings from an eight-year study conducted by Bompangue *et al.*, (2009) where the spatial distribution of cholera cases in the region (among 73,000 cases recorded between 2000 and 2007) were higher bordering lakes.

Table 6.1 shows the number of cholera cases reported in sub-Saharan Africa in 2012 (WHO, 2012). Not surprisingly 75% of cases and over 78% of deaths were represented in three conflict and post conflict affected countries: DRC, Uganda and Sierra Leone. Health systems in conflict and post-conflict areas are more likely to be under functioning or non-existent.

Table 6.1: Cholera cases and deaths in the 6 most affected countries (01 Jan -09 Dec, 2012)

	Cases	Deaths	CFR%
DRC	31994	772	2.4
Sierra Leone	22737	296	1.3
Ghana	8460	83	1.0
Guinea	7321	128	1.7
Uganda	6326	135	2.1
Niger	5283	110	2.1
TOTAL	82,121	1,524	1.9

Source: WHO (2012)

McPake *et al.* (2015) compare northern Uganda in 2000 with Sierra Leone in 2014 to identify common risk factors associated with conflict as a determinant of EVD emergence and transmission. Sierra Leone experienced 11 years of civil war between 1991 and 2002, killing over 50,000 persons and displacing almost two million people (Smille & Minear, 2004). In 1996 only 16% of health centres limited to the capital Freetown were functioning (Gberie, 2005). When EVD emerged in Sierra Leone in 2014, post-conflict economic development and public infrastructure had recovered little. During the emergence of EVD in northern Uganda in 2000, the Acholi region had experienced almost 14 years of 'conflict' and the majority of the Acholi people were internally displaced into 'protected villages' where overcrowding and unhygienic living conditions were experienced, under a government policy to provide 'security' and tactical advantage over the insurgents. The experience of the Acholi forced to live in camps for almost 30 years subjected to disease, poverty and cultural devastation cannot be separated from the emergence of disease outbreaks including EVD in 2000.

Uganda currently is host to the worlds third largest refugee population (UNHCR, 2017) and a policy of organising 'refugee settlements' have replaced the traditional camps to encourage integration, as repatriation for many Congolese, South Sudanese, Somalians and Burundians is not yet a viable option. Around Lake Albert bordering DRC with Bundibugyo and Kibaale districts the influx of new settlers imposed on the existing population has led to competition over fishing, frequently causing clashes with host communities. In response the Ugandan government has relocated many of the more recent refugee settlers to inland areas in Bundibugyo and Kibaale districts where they are given small plots of land to cultivate (UNHCR, 2014). In addition to the increased land and food sources, growing populations among these rural communities in the region have put severe pressure on already overburdened and weak health systems (Basiime, 2015).

Supporting the rhetoric that 'disease has no borders', normally reserved as an argument limited to the geographical spread of infectious disease across borders, it is not a coincidence that EVD outbreaks have disproportionately 'emerged' between countries and their direct neighbours affected by wars and conflict even several years after the conflicts have ended but where health systems and means of sustainable livelihoods have eroded or become overburdened as a result.

Poverty and war and the subsequent displacement of communities are the contextual reality for the people in western Uganda and disease emergence including EVD are its symptoms. Obscuring the larger structural determinants from the global health narrative by

shifting responsibility for poor health outcomes onto the affected individuals themselves perpetuates the social inequalities and misunderstandings that underlie the emergence of these outbreaks.

6.5 Consequences of Exceptionalisation

The theme of ‘exceptionalisation’ emerged from the analysis and is positioned under the second objective of the study because it offers meaning to how the two EVD outbreaks and the response interventions towards them were locally understood [Data Presentation 5.1]. As outlined above a culturally determined epidemiology of EVD has been exaggerated and exoticised by western media and has emerged into western consciousness. Some of the exaggerated narratives and exotic imagery commonly used to describes EVD were presented in the first two narratives of Data Presentation 5.4.2.1.

At both case study sites it was the response interventions that followed the official announcement of EVD that were locally perceived as extraordinary. Intervention came in the shape of a humanitarian emergency response through implementing organisations coordinated under the WHO in collaboration with the MoH in Uganda.

The local community and health workers witnessed the importation of a western public response in terms of resources, financial flows, technical assistance and systems that were rapidly put in place (Data Presentation 5.1.2.1). The political will, national and international media reportage towards the outbreaks also influenced the understanding that EVD itself was an exceptional disease when compared to the everyday challenges experienced in Bundibugyo and Kibaale such as cholera outbreaks and persistent insecurity. Prior to an official diagnosis of EVD the participants in the study described the clinical features of the disease as not dissimilar to other endemic conditions manifesting with fever and diarrhoea such as malaria, typhoid, cholera or diphtheria [Data Presentation 5.1.1].

Following their involvement in the international response phase of the outbreaks a sense of importance surrounding EVD emerged [Data Presentation 5.1.1.2] and reference to endemics previously experienced such as cholera or typhoid were considered less serious [Data Presentation 5.1.1.4]. Retention of staff to manage the EVD outbreaks was motivated by the external organisations through financial and other incentives (Data Presentation 5.1.1.3) and this also influenced the local perception that EVD was exceptional.

The framing of a disease as exceptional from other diseases has had problematic consequences in the past. For example, decades of interventions in response to the HIV/AIDS pandemic resulted in diverting scarce human resources for health away from core health system strengthening (Smith & Whiteside, 2010). It has also contributed towards stigma and self-stigma among those infected (Cameroon, 2006; Kelly, 2006). In this study the exceptionalisation of EVD particularly the exoticised narratives that grew around it in western media resulted in misunderstanding of the disease with serious consequences for the communities in Bundibugyo and Kibaale in 2007 and 2012 respectively. For example, a dominant global narrative that EVD assured a gruesome death in the absence of a cure manifested locally as fear, panic and stigma.

6.5.1 Misdiagnosis

Prior to the West African outbreak EVD was inappropriately referred to as ‘Ebola Haemorrhagic Virus’. As previously outlined this term was influenced by a westernised media hyped image (Sontag, 2001; Preston, 2004; BBC, 2014; CNN, 2014) and ‘Ebola facts’ that outlined major haemorrhage as symptomatic for the disease and its diagnosis. It is now known that haemorrhagic symptoms are witnessed in less than 7% of cases (Bitekerezo *et al.*, 2002). Although EVD outbreaks have been recorded since 1976 a more critical analysis of the most common clinical presentations had not been captured scientifically. A misperception that major haemorrhage is symptomatic for diagnosing EVD resulted in dismissal of cases, further transmission of infection and subsequent infection and death for those exposed. Data Presentation [5.4.2.1] captures how the disease was framed internationally as a haemorrhagic disease and several excerpts from the data made reference to expectations of these ‘facts’ and were subsequently responsible for non-diagnosis or misdiagnoses of positive cases.

This demonstrates a serious consequence of the knowledge imbalance in global health, where local knowledge is excluded from the global narrative surrounding EVD outbreaks. The findings from this study provide evidence that certain ‘facts’ are in fact misinformation and have filtered through sources external to the contexts where outbreaks are experienced as truth. The study conveys a stark contrast between the ‘global’ literature and what several participants witnessed from managing patients in both case studies. In Bundibugyo and Kibaale participants reported the disease as ‘atypical’ because it presented without haemorrhagic symptoms. Reports that the disease presented as ‘atypical’ were also

recorded by local participants from other studies but were not validated. During the West African outbreak medics from the global north recorded several clinical cases they witnessed in ETU's and reported that haemorrhagic symptoms were not as common as previously perceived. Findings captured by western experts are validated as 'new' knowledge conveying how the world is viewed and narrated through the eyes of the global North (Connell, 2007). These northern theories become universal 'truths' because those who convey them hold the power over knowledge for all societies (Comaroff & Comaroff, 2012).

6.5.2 Fear and Abandonment

In the study fear was generated from the type of framing around EVD captured in Data Presentation [5.4.2.1] that infection with EVD resulted in imminent and gruesome death and there was no specific cure. The resultant fear manifested as health workers and patients fleeing from health units in Bundibugyo and Kibaale [Data Presentation 5.4.2.3]. This resulted in several negative consequences for those who became infected and their families. These consequences included experiences of physical confinement, denial of treatment and death for infected patients. For those who survived stigma, social isolation and economic hardship were experienced [Data presentation 5.4.2.5]. The official announcement of EVD was the trigger that incited fear into the community based on their pre-existing perceptions of the disease. In the absence of ever witnessing an EVD outbreak the exceptional narrative surrounding the disease may have influenced these perceptions. This fear manifested as panic and mass abandonment of health workers and patients from health facilities. A similar situation occurred in Gulu and Mbarara in 2000-2001(Kinsman, 2012).

A sudden realization by health workers, who had attended to infected colleagues and patients, that the condition they were managing was EVD had to wait out the incubation period of twenty one days to confirm if they were infected or not. This resulted in severe anxiety experienced by these individual throughout that interim period [Data Presentation 5.4.2.2].

6.5.3 Stigma & Social Isolation

Stigma and social isolation was identified in the Bundibugyo and Kibaale case studies [Data Presentation 5.4.2.5] as in previous studies in Uganda and elsewhere (Kinsman, 2012; Matua, 2014; Okware, 2015). Some participants reported experiencing stigma and social isolation within their communities several years following infection or association with infected persons. Two participants reported how they experienced problems between marriage partners. In one case a wife left her husband taking their only child because she believed that there was no cure.

6.5.4 Containment and Neglect

Fear also manifested in the form of physical confinement and neglect for patients suspected or confirmed to be infected with EVD [Data Presentation 5.4.2.4]. The data identified situations where patients found themselves confined in an isolation unit without access to basic treatment, and in some cases food was denied for a number of days.

we knew that Ebola it has no medicine, it can not be cured, so once we isolated them, we knew that they are there to die, even if we couldn't give them food, people feared to go, to come near them so that is how they were neglected, even them they had that feeling that 'you people, you have gathered us here, waiting for us to die from here' (IDI, K4)

The literature (Section 2.7.2) also identified the issue of patients being neglected by health workers who feared to provide care during the West African outbreak. The concept was referred to by one author as 'therapeutic nihilism' (Lamontague *et al.*, 2014, p.1565). In Liberia children orphaned by Ebola during the West African epidemic were reported as left to die in quarantine as a result of fear by care givers to intervene (Abramowitz, 2015, N.p).

Containment has been described in other EVD outbreaks imposed through militarisation by local, national and international forces. In the Kibaale study containment was undertaken with assistance from the police force at the local level. Okware (2002) refers to "security agencies" that were involved in the coordination of the Uganda outbreak in Gulu in 2001. During the West African outbreak the Liberian government deployed the national military to establish a *cordon sanitaire* at West Point that resulted in violent clashes between

government forces and the local community (Gostin & Friedman, 2015). In the later stages of the West African outbreak an international response to containing the spread of the outbreak came in the form of mass military deployment of foreign troops from USA and European states under the mandate of UNMEER. In contrast during the same outbreak a nurse returning from Sierra Leone to the USA successfully challenged a quarantine measure implemented by the governor of Maine (USA) because it restricted her rights as an individual and contributed to potential stigmatisation (Gonsalves & Statley, 2014; Royo-Bordonada & García, 2016). This highlights a contrast between 'global' response interventions experienced by Africans subjected to militarised containment and citizens from the global North where protection for their individual rights to freedom is considered during EVD outbreaks.

Larkan *et al.* (2015) considers the shift from humanitarian to militarised response mechanisms during the West African outbreak as something that should not go unnoticed. Recognising a power dynamic Larkan *et al.* (2015) asks to what extent have issues of national sovereignty and individual independence been jeopardised by the occupation of international armed forces in West Africa on the basis of 'global health security'? What precedent does this set at the international level and would a similar situation be acceptable between two nations in the global North in the event of a perceived or actual disease outbreak? In the absence of a mandate or international policy on the rights of individuals during EVD outbreaks imbalances between 'global' health security and security of the individual remain questionable. In this study communities supported the containment of affected or suspected individuals because of their fear of the disease.

The consequences of EVD exceptionalisation can be understood through the social amplification framework of risk (Kasperson *et al.* 1988). This framework states that risk events interact with individual, psychological, social and other cultural factors in ways that can increase or decrease the public perception of risk. Amplification of risk perception among groups can influence behaviours that cause secondary social or economic impacts that increase the physical risk itself. For example in both case studies, following official announcement of EVD the immediate response was fear and panic among a large group of health workers and patients within the health facilities. This is an example of a secondary behaviour from the initial perception that Ebola is a killer disease that has no cure. The fear and subsequent panic is referred to as a ripple effect caused by the amplification of risk perception (Kasperson *et al.*, 1988).

Whilst the use of military intervention may appease the general or international population in terms of their perceived security to perceived risk, it can be detrimental to the welfare of the individual where admittance to an Ebola isolation unit in a resource poor context does not necessarily transpire into access to a life saving interventions. Exceptionalisation of a disease as outlined above through exaggerated narratives influences public perceptions to support such extraordinary interventions. The process of generating universal support such as militarised interventions and containment of suspected individuals during EVD outbreaks may also indicate the emergence of a ‘cultural hegemony’ as outlined above in section 6.2.2.

Policies that enforce containment particularly in contexts where resources for patient management may not be forthcoming can emerge into violence against health service providers as evidenced during the west-Africa epidemic (Heymann *et al.* 2015). Fear of confinement and mistrust in health officials was one of the major contributing factors towards the amplification of the outbreak in West African for example (Heyman *et al.*, 2015).

6.5.5 Ethical Concerns during EVD Outbreaks and International Power Dynamics

In the Kibaale and Bundibugyo case studies, ‘global’ interventions also resulted in a high level of external control over management of the outbreaks, the communities and individuals. In Data Presentation [5.4.1.6] reports were captured where EVD survivors surrendered their blood samples to foreign medical personnel for what they assumed was a monitoring exercise. One participant mentioned a consent form but was unclear of its meaning. These events raise some ethical concerns because both participants who had samples taken did not seem clear about a process of informed consent or the purpose of the intervention. The United States Presidential Commission for the Study of Bioethical Issues (2016, p. 5) states that informed consent, at the cornerstone of ethical research, is a fundamental way that researchers demonstrate respect for persons. However the same report goes on to state that ‘public beneficence requires that bio-specimens are collected from infected individuals during public health emergencies because it is the best and only time to advance research about a disease’. In 2010 the Centre for Disease Control was awarded a patent on the commercial product EboBun for vaccine preparation (Patent No. CA2741523A) derived from samples taken during the Bundibugyo outbreak. The Universal Declaration of the Human Genome and Human Rights outline a key number of

points that include that human biological products cannot be used for commercial purposes without the informed consent of the patient and that the patient is entitled to a share of the profit (UNESCO, 2005). Article 21 of the Council of Europe's *Convention for the Protection of Human Rights and Dignity of the Human* states that

The human body and its parts shall not, as such, give rise to financial gain.

(Council of Europe, 1997)

Again a dynamic between a 'global' public good or 'benefice' versus the rights of the individual in African contexts during EVD outbreaks emerges. In 2008, the Indonesian government withheld avian influenza strains insisting that poor countries should get a share in the benefits derived from vaccine development for rich markets (Chen, 2015).

Issues concerning the disparities between accesses to innovative drug therapies for infected individuals from the global North versus West Africans also emerged during the West African outbreak (Royo-Bordonada and García, 2016). Several international health workers who became infected with EVD were medically evacuated to their home countries where they had access to critical care treatment within robust health systems. The justification for this is that it serves the interest of the majority to keep health workers alive in the field (Donovan, 2014). However preferential treatment was not made available to the 800 West African health workers who lost their lives from an already depleted health workforce (Heyman, 2015). This reflects a disparity and inequality in health outcomes between global regions. The consequences of disease exceptionalisation have been outlined and convey the disempowerment experienced by individuals and communities at the local level during the two outbreaks.

The consequences of EVD exceptionalisation to drive a securitised agenda as a 'global' public good or altruistic intervention are biased towards serving the interests of wealthier nations at the expense of individual lives and security in African contexts (Fig. 6.2). This is also evidenced by a lack of political will and policy intervention towards health system strengthening in the global health security agenda [Data presentation 5.2.3].

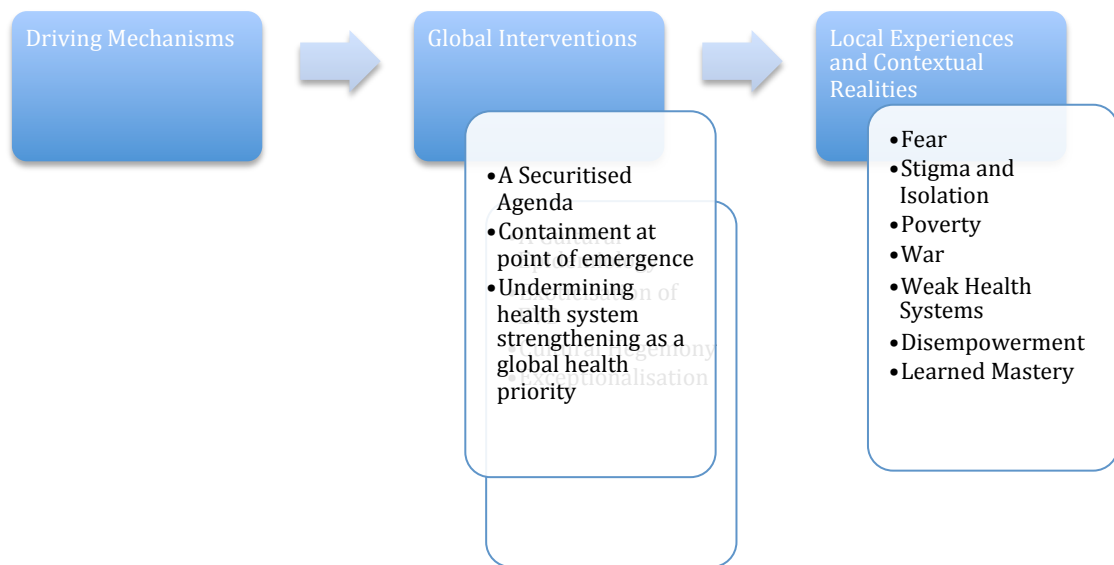


Fig. 6.2 Global interventions and local experiences to EVD outbreaks in western Uganda.

6.6 Empowerment

Hidden beneath the theme of disempowerment emerged several incidents that demonstrated agency among the participants, particularly in relation to the period prior to the arrival of external intervention [Data Presentation 5.5.1]. Most media and scientific reports describing the Bundibugyo and Kibaale outbreaks refer to the management and control of the situation as an intervention totally undertaken by external institutions and organisations. It portrays an image of the local community and health workers as passive victims of a crisis. However few studies have focused on the interim period or the aftermath of these interventions that capture or measure the capacity and role of the local population towards EVD outbreaks (Matua, 2014).

6.6.1 Experiences of Disempowerment

From the analysis several incidents experienced by the participants represented both objective and subjective experiences of disempowerment. Participants who became infected with Ebola virus experienced objective disempowerment through the loss of personal freedom, neglect and socially through stigma and isolation outlined above. Subjective disempowerment was also identified in that participants felt an absence or loss

of control and independence in decision-making processes within the health system, lack of economic and political agency to enact change to their circumstances, a lack of resources to implement basic protocols and preparedness strategies for future outbreaks [Data Presentation 4.2]. What are perceived as unique humanitarian responses [Data Presentation 5.2.1.1] also reveal narratives less evident in the global literature [Data Presentations 5.2.2 and 5.2.3].

The consequences of disease exceptionalisation and subsequent exceptional modes of response convey the disempowerment experienced by individuals and local communities during the two EVD outbreaks and are supported by the literature. Disempowerment was also experienced psychologically through experiences of despair and helplessness [Data Presentation 4.2.1.5].

The literature described ‘the existence of social structures which constrain individual agency’ (Parker, 2003; Schoepf, 1995; Farmer 2005) referred to as structural violence (Galtung, 1969). Examples of structural violence were identified in the study under the social and political realities of Bundibugyo and Kibaale [Data Presentation 4.3.1 and 4.3.2]. The majority of participants in this study had worked within the health system in western Uganda under the social realities outlined in Data Presentation [4.3] for over ten years and had learned to cope with these realities and the structures of disempowerment imposed on them.

The perception of disempowerment or loss of perceived control is linked to the substantive psychological theory of ‘learned helplessness’ (Seligman & Maier, 1967). Earlier theories maintained that learned helplessness is a passive state where a person learns that the outcome of events is independent of their responses to those events. This was believed to be a learned behaviour or tolerance that was observed when a person experiences prolonged uncontrollable aversive events that they fail to escape from, referred to as inescapable stress (IS). This state of learned helplessness is also associated with deficits to motivation, cognitive deficits such as having difficulty in relating responses to outcomes and emotional deficits in terms of a depressed effect by learning that outcomes are independent of response. In other words nothing one did matters and this undermines a desire to escape. This theory may explain how the participants endure not only the everyday challenges of living and working in the contexts of Bundibugyo and Kibaale but also allowed them to cope with managing the EVD outbreaks for long periods without external support.

6.6.2 Learned Helplessness and Learned Mastery

The interim period in both case studies identified resilience portrayed by all levels of staff and management as they persevered to respond to a serious infectious disease outbreak with the available knowledge and resources that they had available to them [Data Presentation 5.5.1.1]. For example the cholera isolation unit at Bundibugyo General hospital and small private rooms in the main wards at Kagadi General Hospital were allocated as isolation facilities. The families of patients were advised to purchase their own gloves and acknowledgement of the role of fluids therapy was prevalent among the participants [Data Presentation 5.5.1.2]. In the Gulu outbreak in northern Uganda in 2000 by the time external organisations arrived to implement a response, Dr. Matthew Lukwiya had installed all infectious control and patient management efforts available to him (Okware, 2012).

The current knowledge base influenced by an exceptional disease narrative surrounding EVD outbreaks emphasise panic and abandonment of health units by health workers during EVD outbreaks. There is also an assumption that a lack of doctors in Africa is a serious resource challenge to managing EVD outbreaks (Lamontague *et al.*, 2014). The skills required to manage patient treatment and infection control within health facilities experiencing EVD outbreaks do not require health cadres trained to the level of doctors or clinical officers. Whilst the study identified several challenges faced by the participants as a result of a lack of basic resources for surveillance, diagnosis, management and infection control, the concept of agency in terms of the knowledge, experience and skills of health workers and their impact on managing EVD outbreaks has never been measured [Data Presentation 5.5.1]. Whilst EVD outbreaks are responded to as something unique or exceptional from the perspective of the international community, it needs to be understood that managing large numbers of patients with few resources available is an everyday reality for health workers in western Uganda. It is this experience and capacity inherent among African health workers that makes them attractive and cost-effective sources of human resources for health sourced by developed countries.

Another feature of agency that have been captured in some previous studies of EVD outbreaks are the coping strategies (Hewlett & Hewlett, 2005; Matua, 2014). Coping mechanisms captured from the data in this study include faith, compassion and social

cohesion within the health settings [Data Presentation 5.5.2.4]. What are narrated as isolated rural and impoverished locations also represent tight communities where there is a strong level of social cohesion [Data Presentation 5.5.2.5]. This is an important tool used during contact tracing where peoples movements and location can be traced through local knowledge. Social cohesion also enables health workers to feel motivated and continue serving their community despite the lack of support available to them from external sources [Data Presentation 5.5.1.4]. This was a major motivating factor in terms of retention and resilience to take control over the situation and continue managing outbreaks, a concept sometimes referred to as ‘learned mastery’.

Expanding from the original studies on learned helplessness described above additional studies found that the experience of control over an event stimulates the prefrontal cortex that in turn blocks the serotonergic activity that originally blocked the escape response. The outcome of this process is that it reverses the behavioural impact of the stressor and subsequent stressors. In other words this physiological process not only reverses the affect of ‘learned helplessness’, but also defends against the neurochemical effects of subsequent experiences where uncontrollable stressors are involved. This physiological process is referred to as ‘immunisation’ (Maier, 2015). Whilst the passive failure to learn to escape is an unlearned reaction due to prolonged aversive stimulation, the process of immunization occurs as a result of experiencing control over aversive events. This suggests that humans can over ride the physiological process of ‘learned helplessness’ (Maier, 2015). In addition this immunization effect is long lasting and trans-situational (Maier, 2015) meaning that it can protect against a variety of stressors in different contexts. In contrast to learned helplessness, this phenomenon of ‘immunization’ is sometimes referred to as ‘learned mastery’ (Seligman & Maier, 1976; Seligman & Maier, 2015). In the study the concept of ‘learned mastery’ was identified from capturing data on a number of experiences where participants conveyed control over aversive events [Data Presentation 5.5.3].

6.6.3 Self- preservation versus ‘poor health seeking behaviour’

Given the fact that the voice of individuals within these communities are seldom heard, the researcher argues that communities perceived as ignorant and backward may be more aware of a highly fatal disease in their immediate environment than what is portrayed by popular media reportage. As described in chapter two, section 2.10, Hewlett and Amola (2003) identified a number of traditional protocols employed during epidemics that

empowered the Acholi community in northern Uganda. During the Ebola outbreak in 2001, the Acholi people employed traditional strategies towards infection control as a rational choice to avoid entering public institutions where there was a deep mistrust for the government. Following the West African outbreak logical reasons why patients feared to enter Ebola treatment units were described, particularly where policies of containment took priority above individual treatment for West Africans (Farmer, 2016).

In Bundibugyo and Kibaale, the community had witnessed first hand multiple deaths within their families or immediate neighbours. By the time that Ebola was announced the community including health care workers panicked and fled from the hospitals where suspected cases had been admitted. Consideration needs to be given to the fact that although the contexts of the two case studies are geographically isolated they are not impervious to social and mainstream media. In these contexts it is not uncommon to find a large social following of European premier league football, high use of mobile banking services and access to international radio channels as part of everyday life. A lack of confidence in public health facilities resulting in abandonment and avoidance must also be considered as a mechanism of self-preservation (Hewlett & Amola, 2003). A realisation that alternative health seeking behaviour during EVD epidemics could be a means of self-preservation rather than a homogenous society of ignorant and primitive people seeking magical intervention. This brings the discussion chapter to a final issue for consideration.

6.6.4 Beyond a Colonial Ideology

How historical conceptions of African society have resurfaced in the discourses of HIV and more recently EVD is often blamed by intellectuals as a legacy of colonialism. Historically racist conceptions of African societies as homogenous entities have greatly influenced the international communities understanding of EVD outbreaks and guided technical response. In chapter two it was argued that a claim made by some authors that the basis to understanding ethnic marginalisation in post-colonial Uganda derives from a 'divide and rule' method used under British colonialism (Blanton *et al.*, 2001; Tornberg, 2012). Evidence from this study and previous narratives surrounding EVD outbreaks support this argument. However it would be an over simplification to attribute all perspectives relating to divisions in identity belonging to a 'superior' versus an 'inferior'

group to be solely influenced by the remnants of colonial ideology and self-diminishment. Whilst colonial powers did facilitate inter ethnic divisions by allying with some groups to defend or suppress others in the policy of 'divide and rule', it would be an over simplification to assume that colonialism was the founding factor of ethnic divides in Africa. Pre-colonial ethnic groups operated independently and were frequently hostile towards each other. This is not a uniquely African phenomenon as evidenced throughout world history. Supremacy imposed deprivation and marginalisation between clans, kinship and ethnic hierarchies existed long before colonialism. The power dynamics and prejudice that exist between groups is a natural social phenomenon within all human societies.

In chapter two Vlopp (2000) posits that in predominantly white societies culture is perceived, as non-existent or raceless and bad behaviour is associated with a lack of rationality or irresponsibility that is not reflected in either racial or ethnic identity nor used to define 'whiteness'. Within nations or groups that are not distinguished from each other by race, the 'us' and 'them' distinctions are made using different labels such as ethnicity, class or religion. During the war in Northern Ireland for example religion was used as a label to differentiate two opposing groups who shared the same race. Similar to what is perceived as a racist perspective towards African culture argued by Vlopp (2003), Africans and Ugandans themselves refer to other Africans, ethnic tribes and minority groups as being less developed, backward and primitive in their beliefs and behaviours.

Both ethnicity and social class are assigned to those who displayed 'bad' behaviour related to EVD emergence at the national and local levels. Labelling individuals into 'us' and 'them' groups has its psychological basis in social identity theory and maybe more relevant to understanding the dichotomy in perspectives relating to the behaviour blame narrative that emerged from the findings in this study. Where 'race' fails to be an effective means to distinguish between the 'good' and 'bad' groups, then an ethnic or 'class epidemiology' is employed. In the Texas case study when irrational behaviour was displayed between two white groups within a predominantly white society then blame was assigned using social class distinctions (Vlopp, 2003).

The historical basis for contemporary political systems, structures and processes in Africa and the norms, rules and traditions that underpin them are rooted in a much more diverse socio-political context that began long before the period of European colonialism (Sesay, 2014). Arguing that the dichotomy identified above between those perceiving themselves to belong to a 'progressive' group versus those they perceive as backward as entirely

founded in colonial ideology may be an over-simplification that assigns too much weight to the legacy of colonialism. In addition the argument that Africans continue to be 'colonised' suggests that they are beyond the ability to possess rational thought independent of their colonial past and are solely guided by principles of historicism. This 'colonialism of the mind' theory that frequently emerges among academics is argued as an outdated theory generated through a northern lens of understanding. It frames Africans as perpetual victims of a colonial past versus a society not unlike any other where divisions between an intellectual or elitist class and those who are less advantaged exists. While the majority of knowledge surrounding EVD outbreaks is captured by health 'experts' from the global North, it sometimes includes the views of this intellectual class captured to inform what goes on around EVD outbreaks 'locally'. However as evidenced from this study this is not necessarily a true reflection of local realities surrounding EVD outbreaks. Human beings from within any group, community, nation or region will display a variety of perspectives towards their own identity and the identity of others that may or may not be determined by culture, history or politics.

From this study those closest to the EVD outbreaks displayed an understanding that their societies are multi-cultural and that behaviour is more likely to be influenced by socio economic rather than cultural factors. The local perspectives conveyed views that displayed more rational thought not necessarily dictated by history.

This dichotomy is interesting as it demonstrates how some voices are heard during EVD outbreaks and others are not. It also demonstrates that the social determinants of EVD outbreaks (outlined above in Section 6.3) can be subordinated to a cultural epidemiology. Unfortunately the 'global' narrative also tends to be dominated by perspectives where culture is portrayed as the main barrier to health outcomes.

6.7 Chapter Summary

Section one explores the 'behaviour blame narrative' that represents a knowledge imbalance around EVD outbreaks between global perceptions and local realities. Within Uganda a dichotomy was identified between national and local perceptions. The imbalanced perceptions outlined above are responsible for narrating a cultural epidemiology of EVD that fail to represent the lived experiences, local contextual realities and their structural determinants in Bundibugyo and Kibaale. In section two, economic

disempowerment is examined in terms of neo-colonial policies and the structures of international development that maintain economic oppression and conflict underlying EVD emergence. In the third section the hidden narratives are discussed in terms of the social realities local responses and their outcomes for the populations of Bundibugyo and Kibaale in western Uganda. In the fourth section the theme of exceptionalisation and its consequences are explored in terms of disempowerment for the individual and North-South power dynamics during EVD interventions. Findings support the argument that the current international system is skewed towards containing the virus from spreading beyond its point of emergence to threaten Western states and therefore fails the people and health systems most affected. Finally empowerment and agency of local communities during EVD outbreaks is described. It is from here that the 'southern theory' or 'local voice' described as the overarching goal of the research comes into view.

Chapter 7: Conclusion

7.1 Introduction

Chapter seven concludes the thesis and highlights the findings and contribution of the work. This final chapter is divided into five main sections. Following the introduction the second section is a reminder of what the study set out to do and how it went about it. Section three summarises the findings under each of the five main themes into subsections. Each of these subsections outlines how each theme contributed towards addressing one or more of the four study objectives outlined in chapter one. Finally within each of these subsections the implications of the findings to policy is outlined. The fourth section of this conclusion chapter addresses the contribution of the study to theory. This section also identifies that the study is not without limitations, therefore some of the key limitations are outlined and where appropriate suggestions are made to address these for future similar studies. Finally recommendations for future research to build and improve on the limitations of this study are outlined. In the final section concluding remarks are made that bring the thesis to a close.

7.2 Justification, Purpose & Methodology

7.2.1 What the study set out to do.

In response to an identified imbalance in the contribution of the local voice to the discourse surrounding EVD outbreaks and evidenced from a review of the literature the following research question was formulated:

What are the contexts from where two Ebola outbreaks emerged in western Uganda in 2007 and 2012, and how are these outbreaks and the external interventions towards them locally understood, experienced and globally determined.

It is believed that a deeper understanding of these contextual realities, local perspectives and lived experiences could confront some of the exotifications and simplifications of current narratives that influence global perspectives about the affected communities and

contribute to a more inclusive and relevant EVD discourse within the realm of global health. From there it is anticipated that a more rationale understanding could inform policy towards interventions that would reflect more sustainable approaches to future EVD outbreaks than are currently being implemented.

7.2.2 How it went about it.

The local voice or ‘southern theory’ was captured using an interpretive approach within the qualitative paradigm. Chapter three outlined the epistemological stance taken by the researcher within the constructivist paradigm using a phenomenological approach. Multiple case study design was selected as the most suitable methodology to meet the four objectives of the study. The rationale for choosing Bundibugyo and Kibaale, the second and third largest EVD outbreaks to occur in Uganda were outlined. Following a rigorous ethics protocol through the researchers home institution and three institutions in Uganda the researcher was given access to the study sites. Purposive sampling was used to identify 25 participants who consented to participate and methods of data collection included digital recorded in-depth interviews, non-participant observation and document analysis. Following transcription the data was analysed using Strauss and Corbin’s cyclic three-step analysis guideline adopted from grounded theory. From here the findings emerged through coding, categorising and the formulation of themes. Five main themes emerged from the analysis: a behaviour blame narrative, structural determinants of delayed diagnosis and nosocomial transmission, social realities, EVD exceptionalisation and empowerment.

7.3 Findings, Objectives Addressed and Policy Implications

To better understand the contextual realities, local, national and global perceptions and lived experiences of EVD outbreaks and the consequences and determinants of their interventions in western Uganda four specific objectives were developed to answer the research question in 7.2 above.

- 1. To understand the contextual realities of Bundibugyo and Kibaale from where two Ebola outbreaks emerged in 2007 and 2012 respectively.*

2. *To understand how EVD outbreaks were perceived locally, nationally and globally in Bundibugyo and Kibaale in 2007 and 2012*
3. *To understand the lived experiences of Ebola outbreaks before, during and in the aftermath of international interventions in Bundibugyo and Kibaale in 2007 and 2012 respectively.*
4. *To understand the determinants and consequences of global health interventions before, during and in the aftermath of the Ebola outbreaks in Bundibugyo and Kibaale in 2007 and 2012 respectively.*

This section links the findings to these four research objectives, their relevance to policy and recommendations for future research.

7.3.1 Theme One: A Behaviour Blame Narrative

7.3.1.1 Theme One: Addressing objective two and four

The first theme that emerged from the analysis, *A Behaviour Blame Narrative* addresses objective two and four of the study. It addresses the second objective by offering perspectives on how the EVD outbreaks were locally, nationally and globally understood. It is from here that the theme of ‘a behaviour blame narrative’ emerged because several references from both case studies reflected a cultural epidemiology that shifted responsibility for EVD emergence and a delayed response onto the behaviours and beliefs of the affected communities understood as a determinant of their ‘culture’. The behaviour blame narrative predominantly emerged from global and national perspectives and those furthest from the outbreaks. None of the frontline health workers assigned blame to the affected individuals. At the local level a dichotomy emerged between those who perceive themselves as health experts from the communities who they perceive as backward and primitive and responsible for the emergence and amplification of EVD. This mirroring of the global narrative was explored further in chapter six under the theory of colonial ideology and cultural hegemony where a division in self-identity between educated Africans elites and the non-educated community was explored. These findings are believed to be significant because previously the theory of ‘cultural epidemiology’ in relation to EVD outbreaks was used to critique how African people, societies and places were formulated as ‘other’ solely through an external racialised lens. The findings from this study convey how the behaviour blame narrative and simplifications of ‘cultural

understandings' relative to EVD is more pervasive and is conveyed at the local as well as the global level. It was argued that the theory of colonial ideology portrays Africans as perpetual victims of a colonial past versus a society not unlike any other where divisions between an intellectual or elitist class and those who are less advantaged exists and may have always existed. Whilst colonial ideology may have contributed to a division in social identity within Ugandan society it is not the basis or only determining factor for its existence in today's society. The first theme of the study also contributes towards addressing the fourth study objective because how a disease is understood informs policy and determines response interventions. The findings from this study convey several understandings from local perspectives that contradict what has dominated the popular and scientific literature, not only around cultural perceptions of EVD outbreaks but also social and clinical understandings of the disease.

7.3.1.2 Theme One: Contribution to policy

Since current understandings at the global level are based on a narrative dominated by a cultural epidemiology, response interventions focus on mitigating risk behaviour and externally led rapid response mechanisms when and where outbreaks occur. The discourse and data sources informing global policy on EVD outbreaks needs a more critical analysis in terms of the knowledge balance between external expertise and local experiences and contextual understandings. Inclusion of local knowledge should not only focus on gathering cultural understandings of local context and behaviours of local communities as research subjects but should be inclusive of local understandings of EVD emergence and the clinical observations of front line health workers managing EVD outbreaks.

7.3.2 Theme Two: Structural Determinants of Delayed Diagnosis and Nosocomial Transmission

7.3.2.1 Theme two: Addressing objective one and three

The second theme that emerged from the analysis addresses the first and third study objective. Looking back at the Bundibugyo and Kibaale outbreaks retrospectively it seems that several lives were lost unnecessary because the voices of impoverished communities, health workers or district officials were ignored. Less talked about in the global narrative

was the lack of response to multiple deaths reported from within communities and lack of support for the health workers who were left to manage the outbreak during a prolonged interim period as they awaited an official announcement as a trigger factor necessary for external intervention. The health workers themselves were powerless to control decisions within the health system. Blame is assigned to individuals for not making decisions from external perspectives. However the political realities and power structures within the health system in Uganda is best understood by those who work within it.

Exceptionalisation around previous EVD outbreaks that filtered through western media generated fear that manifested in local public response as panic and sometimes violence. It is the anticipation of such a public response that played a part in influencing the government to delay disclosing information under a politically sensitive circumstance. International actors and health institutions have blamed state governments for delays or non-disclosure of epidemics that have threatened 'global' health security in the past. However poor governance in responding to potential international public health events is not only limited to those inside national borders. Ironically despite the revision of the IHR in 2005 to mitigate the risk of depending on the transparency of national governments to announce such events that may pose a threat to international security, the delay of the WHO to announce the West African outbreaks as a PHEIC conveys that the problem is in fact global, conveying disparities between regions. A large volume of literature emerged following the West-African outbreak critiquing the WHO and the disarray of the global health landscape in terms of delayed response (Gostin & Friedman, 2014, 2015; Heymann *et al.*, 2015; Horton, 2015; Larkan *et al.*, 2015).

Despite the perception that responses were perceived as unique within the context, closer inspection identified that a greater emphasis was placed on resources that facilitated containment of EVD in Bundibugyo and Kibaale versus provision of basic critical care to infected patients. Patients experienced physical disempowerment through constraint and neglect in health facilities described as a consequence of exceptionalisation. From deductive analysis a contrast was observed between the disparities between global health security and security of the individual across a North-South divide. Deductive analysis also identified similar disparities during the West African outbreak where provision of innovative treatments and vaccines were made available to westerners but not to Africans. Survivors of the virus experienced vulnerability during their recovery when foreign researchers collected their blood samples without transparent process of informed consent. Disempowerment was also identified when survivors, their families and health care

workers experienced stigma and isolation within their communities and families.

7.3.2.2 Theme Two: contribution to policy

The hierarchal structures, power dynamics and institutional barriers in the decision making processes that result in delayed responses to EVD outbreaks cannot remain hidden behind a narrative that blames delayed intervention on culture alone. Gostin & Friedman (2015) argue that grassroots organisations in developing countries are excluded from WHO governance forums because they do not meet the criteria of 'international memberships'. Countries that experience EVD outbreaks have a seat at the UN and are represented globally, but perhaps the dichotomy identified in this study between an elitist cohort and those less advantaged at the community level creates a barrier to facilitating the representation of local knowledge at global forums because of their position low in the hierarchical structure of their societies. Impoverished rural communities and marginalised ethnic groups remain beyond the realm of 'universal consensus'.

There are several areas relevant to medical ethics identified in this and other studies. For example during the West African outbreak ethical issues emerged in terms of informed consent, intellectual property and prioritisation of medical services and access to innovative drug therapies limited to westerners.

Policy analysis on the inclusion of bioethics, state sovereignty and security of the individual during EVD response interventions is an area that requires a lot further consideration. In particular consideration needs to be given to the legislative, diplomatic and organisational structures developed and maintained during emergency response situations particularly where securitised models of intervention are engaged. For example, in the Great Lakes region where conflict and war continue within and across state borders, supporting a securitisation approach towards future EVD outbreaks using national military forces funded by international governments could result in an even more inflammatory situation.

7.3.3 Theme Three: Social Realities

7.3.3.1 Theme three: Addressing objective one and three

The third theme of the study '*a social epidemiology*' addresses the first and third objective of the study. The majority of the participants in the study refer to several social determinants that convey the contextual realities of Bundibugyo and Kibaale that underlie the emergence and magnification of EVD. These were located under the categories of weak health systems, war and poverty. This 'social epidemiology' was again subordinated to the 'behavior blame narrative' in the media and scientific literature described under theme one. In chapter six a deeper analysis linked these social determinants to the larger structural forces of a global capitalist system that maintains the inequalities in health outcomes experienced by the communities of Bundibugyo and Kibaale. Liberalisation policies and their subsequent unfair market advantages underlie poverty for the majority of the population in sub-Saharan Africa who rely on small-scale farming and cash crops. Bundibugyo and Kibaale are no different. A scramble for global commodities in eastern DRC neighbouring Uganda feeds into this globalised economy at national, regional and international levels. This has resulted in decades of war, death and displacement for millions of Congolese, particularly over the past two decades pouring over the border to western Uganda. Exponential population growth added to displaced populations as a result of political conflict and war conveys a political ecology where subsequent competition for land and food resources result in increased contact between humans seeking alternative livelihoods and wildlife habitats. Add to this the overcrowded informal settlements, lack of clean water and sanitation services, poor nutrition and an overburdened and under resourced health system that define the contextual realities of western Uganda. Without political stability and economic development robust health systems cannot exist. These combined social political and ecological factors provide a perfect storm for the emergence of infectious diseases, including EVD similar to the contexts from where EVD outbreaks emerged in the past.

7.3.3.2 Theme Three: contribution to policy

The WHO Commission on the Social Determinants of Health advocated that national and global public policy should embrace evidence on the social determinants and the

interventions and policies that will address them. According to Marmot (2005) responses to health inequalities require more effort into controlling major diseases, improving health systems and to address the social determinants of health by relieving poverty and improve the circumstances in which people live and work.

As evidenced from this and other studies international responses towards EVD outbreaks are based on rapid response or humanitarian type collaborations coordinated through national governments. These are quick fix superficial measures that focus on rapid containment of outbreaks that ignore any of the larger underlying determinants. A common driving force shared by all EVD outbreaks to date in sub-Saharan Africa and particularly evident in the West Africa Ebola epidemic was the deterioration or lack of basic health infrastructure, yet little global health funding is aimed at health system strengthening as a more sustainable approach to responding to epidemics under current global policy approaches. Following official announcement that the EVD outbreaks were over, an active process of reverting things back to 'normal' occurred. Research studies or reports from the scenes where EVD outbreaks occurred in the aftermath of the crises are rarely captured. This study broadened its focus beyond the spotlight of the response phase of the two outbreaks to include the interim period prior to official announcement of EVD and the aftermath as it was observed at the time of data collection in 2014. This allows a comparison to be made between the strength of the health system in terms of response capacity prior to the official announcement of EVD and the capacity of those same health services two and seven years following the outbreaks.

Comparative observations within the health facilities in the aftermath of these interventions were considered and demonstrated that the international response interventions towards EVD outbreaks in Bundibugyo and Kibaale did little to support health system strengthening in general or in preparation of future epidemics. This conveys an inequity in international health where certain diseases are perceived and acted upon as global health crises while other crises of greater magnitude and frequency affecting communities in sub-Saharan Africa are ignored. The dominant global powers controlling the decision-making processes in global health intervene because they perceive EVD as a major threat to them. The current strand of thinking held by global policy makers is that development of a global network that emphasizes surveillance and rapid response will improve mechanisms to containing epidemics and contribute towards improved outcomes. A serious global public health agenda on strengthening public health system infrastructures which went a long way to controlling emerging infectious disease in Europe and North America in the nineteenth

century, has yet to be prioritised as a response mechanism for responding to ‘emerging infectious diseases’ in low-income countries today.

This highlights the need for global health policy to engage in more sustainable approaches to EVD outbreaks. This requires a shift from reactive resolutions such as militarised interventions and medico-technological advances which might not always be relevant or affordable to low-income countries towards the broader structural determinants of epidemics. A stronger engagement and appreciation of the role of interdisciplinary research such as anthropology and political ecology disciplines can go a long way to acquiring this broader understanding of EVD emergence to inform response.

7.3.4 Theme Four: EVD Exceptionalisation

7.3.4.1 Theme four: Addressing objective two, three and four

The fourth theme of the study contributes towards addressing the second, third and fourth objectives of the study. External response interventions towards the two EVD outbreaks were locally perceived as unique when compared with the endemic realities prior to and in the aftermath of the interventions within the context of Bundibugyo and Kibaale. Prior to the West African outbreak ‘facts’ about EVD were disseminated globally and were influenced by an exceptional narrative surrounding EVD as a ‘haemorrhagic virus’. In chapter six the exoticisation of EVD was further explored as a racial expression of the disease embedded in colonial ideology. Most of the lived experiences described in the two EVD outbreaks in this study reflect the consequences of EVD exceptionalisation described above. Under the category of experiences of fear and anxiety health workers and patients perceived that death was an inevitable outcome of EVD. The fear that manifested as abandonment of health facilities together with stigma and social isolation experienced by health workers and survivors of infection was not a new phenomenon that emerged from these findings. Confinement and neglect of patient treatment seemed logical for those informed by a global narrative that stated there was no cure. These were the lived experiences for several victims of EVD including health workers who became infected and died as an outcome.

Justification for a global security agenda around EVD is facilitated by exceptionalisation as an instrument to generate a ‘universal consensus’ to expand risk perception among the

general population. This facilitates a universal consensus towards global health security and securitised response strategies as a global public good and the emergence of a cultural hegemony. It was argued that the One Health concept has been hijacked as a ‘soft power’ tool to generate universal consensus among policy makers in the region.

7.3.4.2 Theme Four: contribution to policy

In terms of policy, the consequences of disease exceptionalisation, while generating a public consensus towards global health security also had serious consequences for the health systems, communities and the welfare of the affected individual.

Exceptional narratives continuously state that there is no specific cure for Ebola. Reference to the importance of fluid therapy in patient recovery was emphasized from participants throughout this study; the nurse who had a miscarriage and whose husband brought her fluids, the health care worker who sought advice from a colleague in Kampala and administered fluids to himself in his house and the community member who refers to the oral rehydration mixture as medicine. This supports a local physiological understanding of the relevance of fluid therapy in treating EVD. As outlined in section 2.1.7 fluids are a relatively cost effective and readily available means of treatment in these contexts yet have only recently been acknowledged as an essential component of Ebola treatment under WHO guidelines (WHO, 2015a). Lamontague *et al.* (2014) stated that fluid therapy is specific treatment for EVD outbreaks and referred to the basic principles of patient care as sufficient for managing EVD outbreaks in West Africa.

Exceptionalisation had also resulted in misperceptions and misinformation that haemorrhagic symptoms were symptomatic for diagnosis of EVD up to very recently. Reporting of haemorrhagic features, as a clinical presentation of EVD could be better defined and classified into major and minor haemorrhagic manifestations. It is now known that haemorrhagic symptoms are witnessed in less than 7% of cases. Although EVD outbreaks have been recorded since 1976 a more critical analysis of the most common clinical presentations had not been captured scientifically. A misperception that major haemorrhage is symptomatic for diagnosing EVD resulted in dismissal of cases, further transmission of infection and subsequent infection and death for those exposed.

There is also a common misunderstanding during EVD outbreaks that a lack of skilled human resources is a major barrier to clinical care in African settings. This is not the case

as the skills required to treat patients with EVD require acute care skills and infection control precautions that the majority of health workers across all cadres are trained and experienced to perform. Again this demonstrates the knowledge imbalance between the global north and south in global health.

7.3.5 Theme Five: Empowerment

7.3.5.1 Theme five: Addressing objective one and three

The fifth theme of the study contributes towards addressing the first and third study objectives. In contrast to disempowerment the theme of empowerment emerged from the categories of agency, coping mechanisms and learned mastery. These categories were identified in both outbreaks where health workers and patients adopted a number of coping mechanisms to survive. In the global narrative, assumptions are made that interventions towards EVD outbreaks are solely the work of external humanitarian organisations and local contribution is non-existent and passive. Themes of agency, compassion and self-preservation were also identified in a similar study undertaken in Kibaale (Matua, 2012).

Whilst community efforts are innovative during epidemics, in the absence of support they are less than desirable in a context where weak health systems exist resulting in considerable social and public health costs including the heightened vulnerability of individuals. While assertiveness and an ability to be resilient under such circumstances conveys agency and independence on the part of the communities affected, it can also have negative consequences where over-confidence can result in over ambitious expectations that may overexpose health workers to infection, stress and an increased workload, where they may become vulnerable to infection. This was reported in several previous studies where health workers who were committed of patient duty lost their lives prior to intervention. In this study several experienced health workers lost their lives during the interim period. The death of Dr. Mathew Lukwiya during the 2000-2001 EVD outbreak in Gulu was also considered a great loss to the Acholi community. In the West African outbreak over 800 health workers were reported to have lost their lives in the line of duty. Loss of health care workers has serious impact on the family, communities and existing fragile health systems.

7.3.5.2 Theme Five: contribution to policy

Inclusion of local perceptions and experiences identify the hidden value of local capacity, the application of universal precautions and the recognition of fluid therapy as a cost effective, locally available and specific treatment option for EVD that can significantly increase survival rates during epidemics. Further studies on the impact of applying primary health care approaches and the input of local capacity during EVD outbreaks in resource poor contexts versus the expenditure on innovative drug therapies and total reliance on external interventions needs further consideration.

7.4 Theoretical Contribution and Limitations of the Study

The findings from this study emerged from the local voices and an understanding of the contextual realities of Bundibugyo and Kibaale districts in western Uganda. The findings also highlighted a knowledge imbalance between local knowledge and narratives dominated by northern scientists and unsubstantiated media reports. These hidden narratives while referred to in previous studies were rarely explored further than providing a background to EVD outbreaks.

7.4.1 Theoretical Contribution of the Study

The study sought to answer a number of research questions by employing an interdisciplinary approach and an anthropological means of analysis to gain a deeper insight into the contexts of EVD emergence and response interventions from global and local perspectives. In this study theories from social and political science, cultural epidemiology, psychology, medicine and critical anthropology were employed to explore a number of hidden narratives that emerged from the findings and link them to larger globalisation processes. This contributed towards a broader theoretical understanding of EVD outbreaks.

The general literature surrounding EVD is dominated by a biomedical model of understanding driven by a behaviour blame narrative currently used to direct response interventions (Figure 7.1). A 'behaviour blame narrative' emerged as the first theme from

the analysis and captured local, national and global perspectives. Recognition of cultural theory surrounding the behaviour blame narrative allowed an analyses of what perspectives are dominant or subordinated, by whom and why. This theme was explored further using the theories of colonial ideology and cultural hegemony. Applying a cultural epidemiology to understanding EVD outbreaks was recognised as limited because it was lacking in an understanding of the broader social factors involved. The ‘structural determinants of EVD diagnosis and nosocomial transmission’ emerged as the second theme of the study from hierarchal institutions and weak health systems identified from the analysis. This theme was further explored through the theory of ‘structural violence’ that linked it to larger global forces that determine the contextual realities of western Uganda. The third theme from the analysis was ‘social realities’ that emerged from poverty and war as social determinants of EVD emergence in Bundibugyo and Kibaale. EVD was perceived as extraordinary within and beyond the study sites and this was influenced through the concept of disease exceptionalisation. Disease exceptionalisation was identified as the fourth theme of the study and the theory of ‘universal consensus’ was used as the basis for understanding how exceptionalisation influences public perception and narratives surrounding EVD. Disease exceptionalisation was also identified as a basis for informing extraordinary response interventions and the social amplification framework was used to explain the process by which risk perception becomes globalised. Risk and crises perception were outlined in the literature review as a theoretical basis to understanding the decision-making processes guiding these responses.

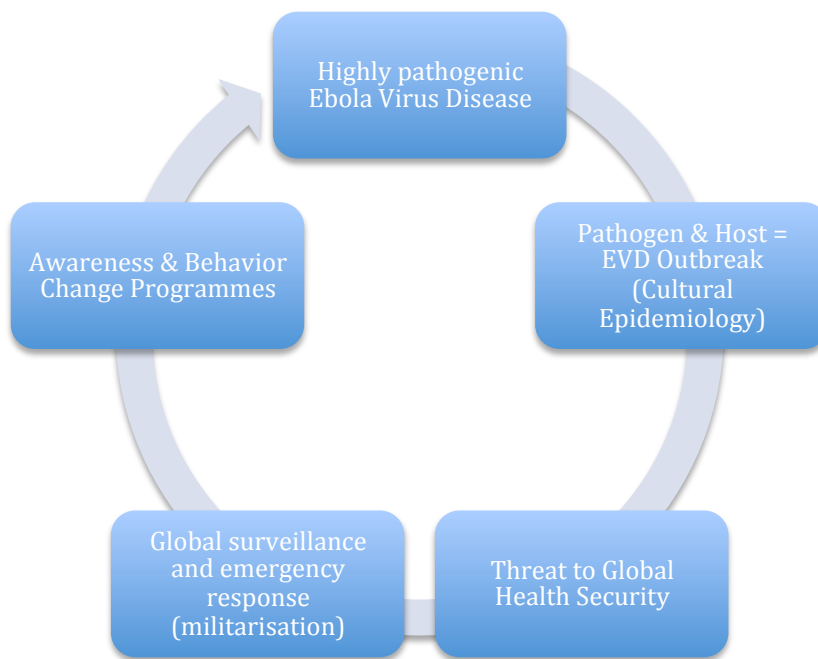


Fig. 7.1 Decision making processes towards EVD outbreaks

The determinants underlying policy decisions and their subsequent interventions towards certain events as global crises can be explored through the theories of altruism and political realism identified from the literature. A power dynamic surrounding EVD outbreaks across a global North-South divide was identified. The final theme of the study, ‘empowerment’ is also considered a hidden narrative as it has been rarely considered previously. The overarching theme of the study emerges as the disempowerment of the individual.

Finally the psychological theories of learned helplessness and learned mastery were used to explain the consequences of disempowerment and empowerment that allowed for a deeper understanding of the lived experiences that emerged.

The Medicoscapes concept was used as a framework to capture the multiple dynamics that emerged from the findings and identify their linkages using theory to global processes.

7.4.2 Limitations of the study

Whilst this study produced credible information that contributes to the field of EVD, it is not without limitations. The following section describes some of these in detail and where appropriate offers suggestion to how they can be addressed in future similar studies.

7.4.2.1 Researcher Bias

The researcher as a foreign national from a high-income country educated in a colonial English speaking system would have entered the context with preconceived ideas and an unfamiliarity with the Ugandan health system that may have contributed research bias to the study. However this was partly mitigated by the fact that she had conducted her MSc. Research in rural Rwanda prior to undertaking this study and remained living and worked in both urban and rural contexts in Uganda and Rwanda for and beyond the duration of this study. Her experiences since then particularly working in a resource scarce public institution for over six years has given her a deeper understanding of the social, political and cultural context of the region.

7.4.2.2 Researcher Effect

Whilst conducting all of the interviews personally had several advantages, limitations of this approach included researcher affect. As mentioned, the researcher, as a non-national of European descent, may have been interpreted as someone who had alternative motives, self-interests or came from a position of power. Media coverage of the West African EVD outbreak was occurring at the time of data collection. Despite the researchers details outlined in the PIL and verbal communication with several of the participants before the interviews, some staff in the hospitals made an assumption that the researcher was seeking to recruit people. One phone call to the researcher about a month following the data collection phase was to enquire about a position to work in West Africa, which confirmed this perception. The researcher may also have been suspected as someone who may have had more information about a risk of an imminent outbreak and was interested in the current capacity to respond. To mitigate this effect each interview concluded with an invitation by the researcher for the participant to ask questions about any of their concerns about the interview or the study in general. The researcher answered all questions to the best of her ability during the data collection period and reminded the participants that she was available to answer any further issues by telephone or email as detailed on the participant information sheet following that period.

Wazungu (whites) were involved in taking blood samples from survivors of EVD during their recovery from the disease. The patients had perceived this as a monitoring exercise but were never communicated to since. Some of the participants may not have trusted the researcher as a consequence, “ *I don’t know if you are connected with them?*”

One of the hospital staff accompanied the researcher during communications with some participants to mitigate this mistrust to some degree. Researcher effect was also suspected when the researcher compared an emerging data category [Data Presentation 4.2.1.1, ‘marginalised communities’] where a lenient attitude from the district toward reports from the community of multiple deaths was identified. This was compared with a district health official’s explanation when asked by the researcher to describe how sudden or unusual deaths in the community are normally managed.

whenever there was an outbreak of a disease, by then we used to have some volunteers at the grass root level called community health workers [] and these are the people who would send information to the health facility, to the nearest health facility and then the in-charge of the health facility could call the DHO [] so that is how information would reach our offices and then from there we would constitute a team of an environmental health staff, a clinical officer, a health educator and a laboratory staff and we proceed to the village where the report came from (IDI, B4)

Researcher affect is suspected where a textbook version of how things should be done versus a more realistic portrayal from several alternative sources was identified.

7.4.2.3 Use of English

The use of English used to interview the participants, particularly in relation to gathering individual perspectives was also recognised as a limitation in the study (Section 7.4.1.1). English represents the language of British colonialism and as such its use has been critiqued as limiting African perspectives in literature (Ngugi wa Thioga, 1986). The interviews may have yielded more liberated perspectives if undertaken in the participant’s native language and this would have strengthened the study in terms of its main purpose of drawing out the southern voice.

7.4.2.4 Respondent Bias

Using semi-structured questionnaires as a guide during the interview process required that the respondents ideally answered the questions honestly and not based on what they perceived to be socially acceptable to the researcher or other listeners. However the possibility of social desirability cannot be ruled out as the majority of participants were public servants working within the Ministry for Health and some may have feared to criticise the government, and therefore been conservative in their true opinions. Others may have felt that they needed to justify that they were performing their duties. Some participants may have felt that this was an opportunity to impress upon the researcher that they were experts in the field. These realities became clearer during subsequent interviews and through other data sources that contradicted some facts. The use of other data sources also helped to overcome recall bias particularly where participants referred to dates. The researcher conducted all of the interviews within the settings where the outbreak occurred from where she could simultaneously observe the context. Documents such as WHO reports and media archives were used to confirm dates and the chronological order of events. This was useful, particularly for the Bundibugyo case study where a gap of seven years has taken place between the outbreak and data collection. A two-year gap existed between the Kibaale outbreak and data collection.

Using audio recording, while having several advantages that make the process of data collection convenient in the field, some participants may have perceived its use as a record that could be used for reporting purposes.

7.4.2.5 Small Sample Size & Participant Fatigue

While the qualitative design for this study was chosen as the most suitable approach for the type of analysis employed and to answer the research questions, it is not without limitations. Having a small sample size means that the findings document a limited number of participants, therefore the study cannot claim to be generalisable to other contexts that experience the same phenomenon.

At the proposal stage only health workers were originally included under the eligibility criteria for the study since the study was focusing mostly on the health system involved in managing the outbreaks. However when presenting the proposal to the Institutional

Review Board at Makerere University School of Public Health in 2014, the researcher was advised to include at least one community member in each study hence the addition of one community member per case study. While this small sample size of community participants is a limitation, the lived experiences of those who became patients within the health units and survived infection included a total of six participants, five health workers and one community member.

Another limitation of using a small sample size is that participants can become over exposed to research studies, a phenomenon referred to as 'respondent fatigue'. The literature reveals that whilst there is a scarcity of theoretical literature on the socio-cultural variables of EVD outbreaks, the number of natural cases available is small. Five studies were identified in the published literature that involved a similar approach to exploring lived experiences using the qualitative paradigm, three of these had been conducted in Uganda and one phenomenological study had already been undertaken in Kibaale district just prior to this study (Hewlett & Amola, 2003; Hewlett & Hewlett, 2005; Matua, 2014). Findings from the Kibaale phenomenological study were similar to the findings that emerged in this study, even to the extent that it was possible to recognize some of the participants through the excerpts documented in the findings. Whilst this defends the dependability of this study, it may also reflect respondent fatigue that can manifest as the respondent repeating a rehearsed narrative in response to familiar questions without reflecting on a deeper meaning of the events retrospectively. There are possibly other anthropological studies being conducted in the region that have not yet been published at the time of writing.

7.5 Areas for further research

Collaboration of international, national and local teams to support the management of epidemics of highly virulent pathogens will remain an important mode of intervention for the foreseeable future in sub-Saharan Africa. However whilst these events are perceived as potential pandemic threats, the burden of such epidemics and their outcomes are mostly borne by impoverished communities and health systems in sub-Saharan Africa. Therefore an emphasis on the type of knowledge most relevant to address these challenges needs to include the perspectives of local community and frontline health workers. Future research then needs to link local knowledge of epidemics and endemics with the larger structural forces of globalisation using the interdisciplinary and trans-disciplinary junctures between

anthropology, medicine, politics, economics and social science and requires a lot further consideration. In this regard the application and limitations of current frameworks that can be used as tools to understand the merging of globalisation processes in the field of epidemics including the One Health concept, Appadurai's scapes, the more recent Medicoscapes framework also require further application and evaluation.

Studies on the processes of globalisation that impact on the perceptions of illness and determine health outcomes in developing contexts are also worth considering. For example this study identified a dichotomy not only between global and local perspectives but also at the local level between frontline health workers directly involved with patients and officials positioned higher in the health system hierarchy with a public health background. This points to a need for further enquiry into the power structures that create barriers to accessing important and relevant knowledge that may continue to be overshadowed by colonial and more recently 'neocolonial' education and 'knowledge' delivered through 'development' partnerships. Findings from this study challenge the argument that assigning culture as the sole determinant for EVD emergence and amplification reflects a racialised expression rooted in an outdated colonial education system. Whether a divide in social identity between health experts and local communities is founded in colonial ideology or social identity theory is an area worth further exploration.

Recommendation for future research is that more studies are needed in the area that capture local perspectives and lived experiences of EVD and other epidemics to address the current knowledge imbalance. Studies capturing the voices of the survivors of the West African outbreaks for example would make a valuable contribution to the existing narrative.

The study provided primary evidence that international and national interventions towards EVD outbreaks in western Uganda failed to consider long term health system strengthening or capture local capacity and experiences learned from the outbreaks.

The area of bioethics and the rights of the individual during epidemics also requires further research and anthropology is well positioned to explore the socio-cultural contexts of disease emergence to inform bioethical principles.

Critical perspectives towards current understandings and interventions to EVD outbreaks are lacking in the policy arena and blind out the structural determinants that maintain its re-emergence.

This disappointment in the limited role permitted by anthropology following the most recent EVD outbreak posits a challenge to the purpose of this study. However rather than abandon the overall purpose of the study it can be used to leverage additional support to continue the conversation towards seeking alternative perspectives and a more critical narrative around current policies and interventions.

7.6 Last Words

Bundibugyo and Kibaale districts represent the sites from where local, national and global actors and institutions converged at a point of intervention aimed at pursuing a common goal; to overcome two major public health crises in western Uganda in 2007 and 2012. The case studies employed in this research explored two EVD outbreaks at their point of emergence, acknowledgement, response and aftermath. While previous studies in Uganda have explored local perspectives during EVD outbreaks, none have linked the broader structural dynamics with the contextual realities on the ground to broaden the understanding from which these epidemics emerged. Even fewer studies have considered the consequences of how 'global' narratives influence policy interventions and their health outcomes for the individual, communities and health systems experiencing these outbreaks at local level.

Despite Uganda being successful in previous efforts to contain EVD outbreaks, individuals and entire families within these communities lost their lives. These losses included experienced health workers within contexts where human resources for health are already scarce thus further weakening fragile health systems. As witnessed in West Africa where fragile health systems exist, entire communities, countries and regions can be socially and economically devastated by a single EVD outbreak.

The main themes that emerged from the analysis were common across both case studies. Bundibugyo is more conflict-affected by the wars in neighbouring DRC, but Kibaale also receives large numbers of refugees from north Kivu. The two case study sites shared similar socio-economic challenges. The response to the Kibaale outbreak in 2012 demonstrated a higher level of political will compared with the Bundibugyo outbreak in 2007. This is a result of several factors including adoption of the International Health Regulations in 2007 and enforced by 2012. Uganda had also experienced a single case in 2011 that may have resulted in an increased sensitivity to the 2012 event. The interventions

at both sites were similar and locally perceived as unique. Also the aftermath at both sites were similar in terms of abandonment of the health facilities following official declaration that the outbreaks had ended. Both sites conveyed little improvements in general health system strengthening or response capacity towards future outbreaks. Both sites reverted back to a pre-outbreak state following withdrawal of external interventions. The contextual challenges described at both case study sites remain the same at the time of writing.

The findings demonstrate that current response interventions towards EVD outbreaks fail to support health system strengthening and are focused on ‘global’ security not necessarily on the security and welfare of the individual in African contexts. This study contributes to the knowledge imbalance in this area by providing a broader and deeper understanding of how globalisation processes impact on the social suffering of the individual. This has important policy implications in terms of the people-centered mission underscored by the United Nations Commission on Human Security. It also has important theoretical implications by conveying the importance of applying anthropology as a means of analysing the deeper dynamics hidden under dominant narratives.

Acknowledgement of these contextual realities and addressing the determinants that underlie EVD epidemics cannot continue to be ignored as a backdrop to their emergence. In addition understanding current international interventions towards EVD outbreaks and their implications for health systems, communities and most importantly the affected individuals is important to ensure that global health security is centered on those most affected. This requires an understanding of the multiple dynamics involved and their linkages at various levels. Understanding the underlying values driving health policy and response interventions from the global level in addition to the social, economic, political and cultural determinants of disease emergence at the local level is important. Only from here can a more inclusive and explicit narrative be developed to inform future policies that can address the underlying determinants of epidemic emergence, develop more sustainable and equitable response interventions and deliver improved health outcomes for individuals. This requires broadening the current application of anthropology in epidemics beyond a tool for cultural understandings of disease to consider the larger structural forces of globalisation processes and policies that impact on the welfare of those most vulnerable.

The main purpose of the study was to deliver a more inclusive narrative to address an imbalance in current contributions to EVD outbreaks by capturing the voices of those who lived through them. Guided by the Medicoscapes Concept the findings have been critically

discussed in relation to the literature and the theory that has contributed to the previous literature on EVD outbreaks and towards informing future policy and planning for EVD epidemics in Uganda and beyond.

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Appendices A - F

Appendix A

Semi-Structured Questionnaire -MoH/Local District Officials

UNDERSTANDING CONTEXTUAL REALITIES AND LIVED EXPERIENCES OF GLOBAL HEALTH RESPONSES TO EBOLA OUTBREAKS ON HEALTH SYSTEMS IN UGANDA: A CASE STUDIES APPROACH

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Participant No. _____

PART A: BEFORE 2007/2012

1. What is your background in the health system before 2007/2012?
2. So how would you describe the health system here, or the hospital/health centre in Bundibugyo/Kagadi at that time before 2007/2012?
3. What were the main diseases that were presented to the hospital at that time, the most common conditions?
4. Was it the health system locally that was responsible for health care in the refugee camps or was it taken care of by the government/international organisations/NGO's?
5. How is Bundibugyo Hospital funded?
6. What is the role of the district health teams? How do they work with the district health officer and the health services?
7. What role did donor organisations play in supporting the health systems in Bundibugyo (Kibaale) before 2007/2012?
8. What systems were in place for surveillance and management of outbreaks before 2007/2012?
9. Did you always have sufficient consumables like gloves, fluids and antibiotics back in those days?
10. How about protective clothing for the staff who worked on these wards? so how would the nurses be dressed, entering and exiting those isolation units?
11. How many times can you remember there being an isolation ward set up in your time here, that it was required to set up an isolation unit?

PART B: THE EBOLA OUTBREAK

12. Moving on towards 2007 (2012), when was it first suspected that there was something more sinister/unusual going on?
13. How was it first suspected or when was it first suspected?
14. What did people think initially, the health care workers think they were dealing with?
15. What process was in place at that time for diagnosing samples?
16. At this point in Bundibugyo Hospital (Kikyoo HC/Kagadi Hospital), how many patients did you suspected were sick with this disease?

17. Do you know approximately how many people died before intervention arrived?
18. Going through each of those people who came from outside and what they did, when they came?
19. What organisations/institutions came? How many came (approximately)?
20. Can you remember how many health workers were trained in infection disease control or from how many health centres?
21. What resources did the organisations/institutions bring?
22. Of those resources they brought what is still here?
23. What systems did they put in place?
24. Were these systems new to you or you had used something similar previously?
25. Would you use these systems again in the case of say another outbreak, do you have the resources to set them up?
26. Do you think if you had an outbreak here in Bundibugyo (Kibaale) next week intervention would be faster?
27. So when new staff came from Kampala or from another district to work here would they be trained in managing an infectious disease outbreak?
28. Did any of these agencies that were involved in different aspects of the outbreaks leave behind any written reports, on infectious disease control or how things were done during the EVD outbreak?
29. And since the responding agencies came in that time, have there been any other agencies that contributed to the health system? Which ones?
30. During this time how were the Ministry for Health co-ordinating these organisations?
31. These meetings you had every day, what was their purpose?
32. So what level (cadres) of health care workers were in these committees?
33. And what did you learn from that process?
34. Who was communicating to the people in the community at that time?

PART C: AFTERMATH

35. Following declaration that the outbreak was over what happened within these systems?
36. How close do you to work with the veterinary sector here?
37. How has life in Bundibugyo (Kibaale) within the health system in 2014, improved or disimproved or has it stayed the same?
38. Which areas have seen improvement?/disimprovement?
39. Who funds those areas?
40. How are the systems of water and sanitation?
41. Consumables?
42. Systems?
43. Human Resources?
44. What was your personal experience during the 2007 (2012) outbreak?
45. How do you see your future in the health system?
46. What lessons did you learn from the experience of the outbreak?
47. What resolutions would you suggest putting in place for future outbreaks?
48. Any other comments?

Semi-Structured Questionnaire – Hospital Management

UNDERSTANDING CONTEXTUAL REALITIES AND LIVED EXPERIENCES OF GLOBAL HEALTH RESPONSES TO EBOLA OUTBREAKS ON HEALTH SYSTEMS IN UGANDA: A CASE STUDIES APPROACH

Caroline Ryan MRCVS, Doctoral Researcher, Earth & Natural Sciences PhD Programme, Trinity College Dublin, Republic of Ireland funded by the Higher Education Authority (HEA) of Ireland through the Programme for Research at Third Level Institutions, Cycle 5 (PRTL-5) and co-funded by the European Regional Development Fund (ERDF). Email: cryanvet@gmail.com, Phone: + 256 772673211, Address: Department of Clinical Studies, College of Veterinary Medicine, Animal Resources and Biosecurity, Makerere University, Uganda.

Participant No. _____

PART A: EMERGENCE 2007/2012

1. What is your position within the hospital/clinic/health care service?

2. How long have you been in this position?

3. What resources does the hospital currently have in terms of:

(i) Infrastructural Resources:

number of wards/ beds per ward

isolation unit

maternity ward

radiology

laboratory diagnostic equipment

pharmaceutical supplies

consumables (protective clothing, gloves, disposable syringes, needles, fluid kits)

clinical waste disposal

morgue

water & sanitation systems

food preparation facilities

Ambulance, driver, fuel

Cold storage for samples

Generator & fuel

(ii) Human Resources:

surgeons

orthopaedic

soft tissue

obstetric

medical

clinicians/medical officers

nurses

midwives

nurse technicians

community health care workers

support staff

Pharmacist

Laboratory technicians

Psychiatrist/psychologist/counsellor

Nutritionist

Radiographer

Radiologist

Ambulance driver

Ambulance attendants

Janitor/ascari

Pathologist

Cleaner/laundry attendants

Kitchen staff

Security staff

Other

(iii) Financial Resources:

4. What are the current sources of funding for the hospital?

5. Has public funding for the hospital increased or decreased over the past 5 years?

6. What are the average staff salaries in the hospital/clinic?

7. What are the average hours per week?

8. Does a budget line exist for emergency disease outbreaks?
9. In your opinion is the hospital currently prepared to manage a serious infectious disease outbreak such as cholera or Ebola?
10. Are there currently protocols in place for the hospital/clinic to respond to a serious infectious disease outbreak in the community?
11. Describe the protocols currently available to respond to such an outbreaks under the following headings?
12. Do opportunities for continuous training exist?
13. What resources are currently available at the hospital to respond to a potential or real emergency/disease outbreak?

PART B: THE EBOLA OUTBREAK

14. When and how was the Ebola outbreak in 2007/2012 first suspected?
15. When and how was it confirmed?
16. What resources had the hospital during that time period to manage the outbreak?
17. During the period between the Ebola infection being suspected and confirmed by laboratory diagnosis describe your experience of the events that took place?
18. How many staff and patients died during this period?
19. How long after laboratory confirmation of the Ebola virus did external support arrive?
20. Describe the events that took place following the arrival of external support.
21. Are those resources still available in the hospital/clinic?
22. Describe the role/functions of the external teams in managing the outbreak response
23. Describe how the external support teams co-ordinated their activities in terms of a management system?
24. How were these systems communicated to the hospital/clinic staff?
25. Was any formal training provided to the hospital staff and management from the external supporters in terms of control of the outbreak?
26. Were health care providers compensated during this period? How much? by whom?
27. During this period how and by whom was clinical waste disposed of?

PART C: THE AFTERMATH

28. In your own words describe your experience of the outbreak.
29. What knowledge, if any did you learn from the external support teams?
30. Describe what happened following withdrawal of the external support – how did the hospital resume its normal function?

31. What lessons did you learn from how the response was organized and implemented?
32. Was a report presented to the hospital following the outbreak?
33. What changes have been implemented in the hospital with management of infectious diseases, if any since the outbreak?
34. What has been the role of the Ministry for Health since the Ebola outbreak was declared over?
35. Is there anything you would do different in the event of a future outbreak?
36. Any other comments?

Appendix C

Semi-Structured Questionnaire – Health Care Workers

UNDERSTANDING CONTEXTUAL REALITIES AND LIVED EXPERIENCES OF GLOBAL HEALTH RESPONSES TO EBOLA OUTBREAKS ON HEALTH SYSTEMS IN UGANDA: A CASE STUDIES APPROACH

Caroline Ryan MRCVS, Doctoral Researcher, Earth & Natural Sciences PhD Programme, Trinity College Dublin, Republic of Ireland funded by the Higher Education Authority (HEA) of Ireland through the Programme for Research at Third Level Institutions, Cycle 5 (PRTL-5) and co-funded by the European Regional Development Fund (ERDF). Email: cryanvet@gmail.com, Phone: + 256 772673211, Address: Department of Clinical Studies, College of Veterinary Medicine, Animal Resources and Biosecurity, Makerere University, Uganda.

Participant No. _____

PART A: EMERGENCE 2007/2012

1. What is your position within the hospital/clinic/health care service?
2. How long have you been in this position?
3. In your opinion is the hospital currently prepared to manage a serious infectious disease outbreak such as cholera or Ebola?
4. Are there currently protocols in place for the hospital/clinic to respond to a serious infectious disease outbreak in the community?
5. Describe the protocols currently available to respond to such an outbreaks under the following headings?
6. Do opportunities for continuous training exist? If yes, how, when and by whom are these delivered?
7. When and how was the Ebola outbreak in 2007/2012 first suspected?
8. When and how was it confirmed?
9. What if any protocols for reporting and diagnosing infectious disease outbreaks were in place prior to the outbreak?
10. How long was the period of time between EVD being suspected and confirmed by laboratory diagnosis?
11. What resources had the hospital during that time period to manage the outbreak?
12. Describe your experience during that time?
13. What alternatives were available to people in the community who feared going to the hospital to receive emergency healthcare?

14. During the period between the Ebola infection being suspected and confirmed by laboratory diagnosis, what support was offered from outside the hospital? By whom?

15. How many patients with suspected EVD who were admitted to the hospital/clinic died during this period?

16. How many members of the hospital staff were infected with suspected Ebola/died virus during that time?

17. Were you compensated during this period?

How much? By whom?

18. How many times per day would you visit/examine a suspected Ebola patient:

19. Describe the purpose of the visit(s)? (clinical exam/visual exam/tissue sampling/nursing care/washing/feeding/social)

20. During this period what was the average time to bury a corpse from time of death?

21. During this period how was clinical waste disposed of and by whom?

22. During this period who fed the patients?

PART B: THE EBOLA OUTBREAK

23. How long after laboratory confirmation of EVD was external support provided? By whom?

24. Describe the institutions/organizations, resources and support structures provided following official announcement of Ebola?

25. Are those resources still available in the hospital/clinic?

26. Describe the role/functions of the external teams in managing the outbreak response:

(i) Within the hospital

(ii) Within the community

27. Describe how the external support teams co-ordinated their activities in terms of a management system?

28. Describe the systems/protocols that were put in place by the external teams to manage the outbreak?

29. Was any formal training provided to you from the external teams in terms of control of the outbreak?

30. In your own words describe your experience of the outbreak.

PART C: THE AFTERMATH

32. Describe the events that took place following announcement that Ebola was over?
33. What knowledge, if any did you learn from the external support teams?
34. How did you apply this knowledge during the outbreak or since the outbreak.
35. What skills, if any did you adopt from the external support teams?
36. How have you applied these skills during or since the outbreak?
37. Describe what happened following withdrawal of the external support – how did the hospital resume its normal function?
38. What lessons did you learn from how the response was organized and implemented?
39. What changes have been implemented in the hospital with management of infectious diseases, if any since the outbreak?
40. What has been the role of the Ministry for Health since the EVD outbreak was declared over?
41. Is there anything you would do different in the event of a future outbreak?
42. Any other comments?

Appendix D

Semi-Structured Questionnaire – Non-Medical Support Staff

UNDERSTANDING CONTEXTUAL REALITIES AND LIVED EXPERIENCES OF GLOBAL HEALTH RESPONSES TO EBOLA OUTBREAKS ON HEALTH SYSTEMS IN UGANDA: A CASE STUDIES APPROACH

Caroline Ryan MRCVS, Doctoral Researcher, Earth & Natural Sciences PhD Programme, Trinity College Dublin, Republic of Ireland funded by the Higher Education Authority (HEA) of Ireland through the Programme for Research at Third Level Institutions, Cycle 5 (PRTL-5) and co-funded by the European Regional Development Fund (ERDF). Email: cryanvet@gmail.com, Phone: +256 772673211, Address: Department of Clinical Studies, College of Veterinary Medicine, Animal Resources and Biosecurity, Makerere University, Uganda.

Participant No. _____

PART A: EMERGENCE 2007/2012

1. What is your position within the hospital/clinic/health care service?
2. How long have you worked here?
3. In your opinion is the hospital currently prepared to manage a serious infectious disease outbreak such as cholera or Ebola? Explain why?
4. During the Ebola outbreak in 2007/2012 describe your role/function at the hospital clinic when the virus was first suspected.
5. Describe your experience before the Ebola was announced and external support arrived?

PART B: THE EBOLA OUTBREAK

6. When did external support arrive to support the hospital during the Ebola outbreak?
7. What organisations were involved in supporting the hospitals during this period.
8. What were their role/function during the outbreak?
9. Did your role change in any way following the arrival of external organisations to the hospital?
10. Describe you experience during the Ebola outbreaks?
11. Did you receive any training during that time?

12. What trainings and support were given to you?

PART C: AFTERMATH

13. Do you have access to the following resources:

(i) Protective clothing, if yes, please describe.

(ii) Gloves

(iii) Virucidal disinfectants

(iv) Foot baths

(v) Clinical waste disposal facilities

(vi) A source of clean running water

14. Who is responsible for implementing an emergency response plan in the hospital/clinic?

15. Describe the events since the Ebola outbreak was declared over?

16. What lessons did you learn from the outbreak?

17. What resolutions would you give for future outbreaks?

18. Any other comments?

Appendix E

Semi-Structured Questionnaire – Patient/Community Member

UNDERSTANDING CONTEXTUAL REALITIES AND LIVED EXPERIENCES OF GLOBAL HEALTH RESPONSES TO EBOLA OUTBREAKS ON HEALTH SYSTEMS IN UGANDA: A CASE STUDIES APPROACH

Caroline Ryan MRCVS, Doctoral Researcher, Earth & Natural Sciences PhD Programme, Trinity College Dublin, Republic of Ireland funded by the Higher Education Authority (HEA) of Ireland through the Programme for Research at Third Level Institutions, Cycle 5 (PRTL-5) and co-funded by the European Regional Development Fund (ERDF). Email: cryanvet@gmail.com, Phone: +256 772673211, Address: Department of Clinical Studies, College of Veterinary Medicine, Animal Resources and Biosecurity, Makerere University, Uganda.

Participant No. _____

1. Describe your experience of the Ebola outbreak in 2007/2012?
2. During what period were you a patient at the hospital/health centre?
3. Were you a suspected or confirmed positive of Ebola virus?
4. Describe your experience as a patient athospital/clinic during the Ebola outbreak in 2007/2012.
5. How many visits did you receive per day from doctor/nurse?
6. What were the purpose of the visits (blood/tissue sampling, physical examination, visual examination, nursing care)?
7. How many visits did you receive per day/week from family members?
8. Were they provided with protective clothing while visiting you in the hospital?
9. Were you provided with food?
10. Were you family members/carers provided with protective clothing?
11. Describe what washing and sanitary facilities were available to you during your period in the hospital?
12. Describe your experience when you were discharged from the isolation unit?
13. What lessons did you learn from your experience?
14. What resolutions would you like to give related to your experience as a patient?
15. Any other comments?

Appendix F

Ethics Approval Letters, Informed Consent Form & Participatory Information Leaflet



COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH | TRINITY COLLEGE DUBLIN
Ollscoil Átha Cliath | The University of Dublin

Caroline Ryan
Faculty of Veterinary Medicine,
Umutara Polytechnic,
Nyagatare,
PO Box 57,
Rwanda

6th March 2014

Re: Understanding the impacts of global public health responses to Ebola outbreaks on local health systems in Uganda: A case studies approach.

Application: 09/2013/07

Dear Caroline,

Thank you for your submission of the above proposal to the HPM/CGH REC.

The REC has given ethical approval to the proposed study.

Yours Sincerely,

A handwritten signature in black ink, appearing to read 'Charles Normand'.

Prof. Charles Normand
Chair of the HPM/CGH REC

An Coiste um Thaighde Eitice
*An Lárionad Pholasal agus Bhainistíocht
Sláinte/Lárionad na Sláinte Domhanda*
3-4 Plás Foster, Seomra 0.18,
Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

Research Ethics Committee
*Centre for Health Policy and
Management/Centre for Global Health*
3-4 Foster Place, Room 0.18,
Trinity College,
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COLLEGE OF HEALTH SCIENCES
SCHOOL OF PUBLIC HEALTH
HIGHER DEGREES, RESEARCH AND ETHICS COMMITTEE

31st March, 2014

Caroline Ryan
Principal Investigator, Protocol (041)
PhD Student, Trinity College Dublin

Re: (IRB00011353) Approval of Proposal titled: Impacts of Global public health responses to Ebola outbreaks on local health systems in Uganda: A case studies approach

This is to inform you that, the Higher Degrees, Research and Ethics Committee (HDREC) granted approval to the above referenced study, the HDREC reviewed the proposal and made some suggestions and comments which you have adequately incorporated:

Note that the initial approval date for your proposal by HDREC is 31st/03/2014, and therefore approval expires at every annual anniversary of this approval date. The current approval is therefore valid until: 30th/03/2015.


Continued approval is conditional upon your compliance with the following requirements:

- 1) No other consent form(s), questionnaire and/or advertisement documents should be used. The consent form(s) must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject must be given a copy of the signed consent form.
- 2) All protocol amendments and changes to other approved documents must be submitted to HDREC and not be implemented until approved by HDREC except where necessary to eliminate apparent immediate hazards to the study subjects.
- 3) Significant changes to the study site and significant deviations from the research protocol and all unanticipated problems that may involve risks or affect the safety or welfare of subjects or others, or that may affect the integrity of the research must be promptly reported to HDREC.



- 4) All deaths, life threatening problems or serious or unexpected adverse events, *whether related to the study or not*, must be reported to HDREC in a timely manner as specified in the National Guidelines for Research Involving Humans as Research Participants.
 - Please complete and submit reports to HDREC as follows:
 - a) For renewal of the study approval – complete and return the continuing Review Report – Renewal Request (Form 404A) at least 60 days prior to the expiration of the approval period. The study cannot continue until re-approved by HDREC.
 - b) Completion, termination, or if not renewing the project – send a final report within 90 days upon completion of the study.
 - Finally, the legal requirement in Uganda is that all research activities must be registered with the National Council of Science and Technology. The forms for this registration can be obtained from their website www.uncst.go.ug. Please contact Mr. Tusiime Wilson, Administrative Assistant of the Higher Degrees, Research and Ethics Committee at wtusiime@musph.ac.ug or telephone number (256)-41-543872 or +256772496136 if you encounter any problems.

Yours sincerely



Dr. Suzanne Kiwanuka
Chairperson, Higher Degrees, Research and Ethics Committee

Enclosures:

- a) A stamped, approved study documents (informed consent documents):



THE REPUBLIC OF UGANDA

OFFICE OF THE PRESIDENT

PARLIAMENT BUILDING P.O.BOX 7168 KAMPALA, TELEPHONES: 2548816, / 343934, 343926, 343943, 233717, 344026, 230048, FAX: 235459/256143
Email: secretary@op.go.ug, Website: www.officeofthepresident.go.ug

ADM 154/212/01

June 25, 2014

The Resident District Commissioner, Bundibugyo District
The Resident District Commissioner, Kibaale District

RESEARCH CLEARANCE

This is to introduce to you **Caroline Sarah Ryan** Researcher who will be carrying out a research entitled **"IMPACTS OF GLOBAL PUBLIC HEALTH RESPONSES TO EBOLA OUTBREAKS ON LOCAL HEALTH SYSTEMS IN UGANDA: A CASE STUDIES APPROACH"** for a period of **fifteen (15) months** in your district.

She has undergone the necessary clearance to carry out the said project.

Please render her the necessary assistance.

By copy of this letter **Caroline Sarah Ryan** requested to report to the Resident District Commissioners of the above districts before proceeding with the Research.

Alenga Rose

FOR: SECRETARY, OFFICE OF THE PRESIDENT

Copy to: Caroline Sarah Ryan

INFORMED CONSENT FORM

PROJECT TITLE: Understanding the impacts of global health responses to Ebola outbreaks on local health systems in Uganda: A case studies approach

PRINCIPAL INVESTIGATOR: Dr. Caroline Ryan, Trinity College Dublin & Makerere University School of Public Health

BACKGROUND

You are invited to take part in a key informant interview using written or audio recording for the above research study. The purpose of this study is to gain an understanding of your experience of events and of the emergency response that was implemented in the hospital/clinic/community during the Ebola outbreak in 2007/2012. The views and opinions from this study will be captured in the results. However your personal identity and responses will be kept in strictly confidential. **Participants can contact the IRB chair Dr. Suzanne Kiwanuka in case of any issues they have concerning their rights and welfare as they participate in the study at 0312-291-397 or 0718 060 387.** If you choose to participate you will a right to a copy of your transcript.

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME:

CONTACT DETAILS:

PARTICIPANT'S SIGNATURE:

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:..... **Date:**.....



PARTICIPANT INFORMATION SHEET

Understanding the impacts of global public health responses to Ebola outbreaks on local health systems in Uganda: A case studies approach

Caroline Ryan MRCVS, Doctoral Researcher, Earth & Natural Sciences PhD Programme, Trinity College Dublin, Republic of Ireland funded by the Higher Education Authority (HEA) of Ireland through the Programme for Research at Third Level Institutions, Cycle 5 (PRTL1-5) and co-funded by the European Regional Development Fund (ERDF).

You are invited to take part in a key informant interview for the above research study. Before you decide whether or not to take part, it is important for you to understand why this research is being done and its components. Please take time to read the following information carefully.

1. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to gain an understanding of your experience of events and of the emergency response that was implemented in the hospital/clinic/community during the Ebola outbreak in 2007/2012. This will help the research by describing and understanding the context in which you work and the resources and systems given to you manage the outbreak. It also aims to understand the impact of external support on the local health system during and following the outbreak.

2. WHY HAVE I BEEN INVITED TO PARTICIPATE?

You have been invited to participate in the research study because you have been identified as a key informant among the health service providers working in the local hospital/clinic/community during the Ebola outbreak that took place in 2000/2007. To meet the objectives of the study your input is very important.

3. HOW LONG WILL IT TAKE?

The questionnaire has in total of 75 questions; many are short answers. In total the interview should not take longer than two hours to complete. Refreshments will be provided during the interview and you are welcome to take a short break during the interview if you wish to do so.

4. WHAT ARE THE BENEFITS/RISKS IN TAKING PART?

The benefits of being involved are that the study allows you to voice your experience of the Ebola virus outbreak as a health service provider. The information you provide will allow the researcher to evaluate how the outbreak was managed and how the management of it impacted on your local health system. Your perspective will help the researcher to understand the context and challenges you as a local health service provider faced in trying to manage the outbreak and on the effectiveness of the international response that came to support you at the hospital.

The data gathered will be used to advise public health actors and policy makers to consider when developing future management plans for similar response strategies within health systems in developing countries. There are no major risks involved in taking part in this study. However some participants may find the experience distressing as the interview process may cause anguish and upset as memories of the outbreaks and losses to close relatives or friends re-emerge. For those who experience anguish during or after the interview, a counselling service is available if they request to discuss in absolute confidence any disturbing issues discussed during the interview. This service will be entirely confidential and independent from the hospitals involved.

5. WILL WHAT I SAY IN THIS STUDY BE KEPT CONFIDENTIAL?

The views and opinions from this study will be captured in the results. However your identity and responses will be made anonymous. This will be achieved by allocating an individual case identity number on the front page of each questionnaire. Apart from responses, no personal details that can identify you will be recorded on the questionnaire. Your identification details linked to the

questionnaire identification number will not be kept with the questionnaires but in a separate place under the sole access of the researcher.

6. WHAT SHOULD I DO IF I WANT TO TAKE PART?

The researcher will contact you on the telephone number you gave her today within the next 10 days and if you agree to participate in the research study a time and date suitable within the time frame of the data collection period will be organized between you and her. She will contact you again to confirm the interview time and date at least 48 hours prior to her arrival. Before you participate in the study the researcher will request you to sign the consent form that you have been provided with today.

The researcher will be available to contact by telephone or email (provided) at any time prior to, during and after the meeting to answer any questions you may want answered in relation to the study or the consent process.

7. WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

The results of this study will be used as part of a PhD thesis on "Understanding the impacts of global public health responses to Ebola outbreaks on local health systems in Uganda: A case studies approach". Results from this study may be published in a scientific journal. Results will also be disseminated to the host institutions involved in the study and to the research funders if they request.

8. WHO IS ORGANISING AND FUNDING THE RESEARCH?

The researcher, Caroline Ryan is a veterinarian and a doctoral researcher under the Earth and Natural Sciences PhD Programme through Trinity College Dublin, Ireland. The research is funded by the Higher Education Authority (HEA) of Ireland through the Programme for Research at Third Level Institutions, Cycle 5 (PRTL-5) and co-funded by the European Regional Development Fund (ERDF). The researcher is also a lecturer at the College of Veterinary Medicine, Animal Resources & Biosecurity, Makerere University, PO Box 7062, Kampala, Uganda.

9. WHO HAS REVIEWED THE STUDY?

This study has been reviewed and approved by the Institutional Review Board, College of Health Sciences, School of Public Health, Makerere University, Uganda and the Research Ethics Committee at the Centre for Global Health at Trinity College Dublin, Ireland.

10. CONTACTS FOR FURTHER INFORMATION

If you have any further questions about the study that you would like answered, you the researcher is available to contact by email: cryanvet@gmail.com or telephone: +256 772673211 or can be contacted in person at the College of Veterinary Medicine, Animal Resources & Biosecurity, Makerere University, P.O Box 7062, Kampala, Uganda.

Thank you for taking time to read this information sheet.

Caroline Ryan