

# EXPLORING THE RELATIONSHIP BETWEEN EPIDEMICS, NARRATIVES, HEALTH POLICY AND THE EXACERBATION OF GENDER INEQUALITY

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## Abstract

Epidemics are not gender neutral. Studies of Ebola, Zika and HIV/AIDS recall that women in the Global South experience disease differently and disproportionately to men socially, economically and in some cases biologically. While there are many complex factors which contribute to this, this research focuses on the ways in which narratives in global health deal with epidemics, gender and women.

This research asks in what ways have global health actors the WHO and CARE International, exacerbated gender inequity and what are the implications for marginalised women. It shows how global health actors exacerbate gender inequality through the kinds of stories they tell about disease and women which in turn, shapes how they are thought about and responded to. It argues that while these stories appear to be harmless, they conceal global health agendas which seek to instrumentalise women and their gendered roles in the prevention, management and containment of disease. This contributes to what can be understood as the feminisation of health (FOH) or the implicit and/or explicit gendered problematisation of disease.

The theoretical framework draws on both Wald (2008) and Leach and Dry's (2010) outbreak and narrative approaches to help identify the kinds of narratives that are used in global health. It also incorporates a gender perspective to help identify the ways in which women and their gendered roles have been dealt with by key global health agencies.

*For William and Sarah*

*For my younger self who thought she didn't have the ability to succeed at university, you did it!*

*"Only those who will risk going too far can possibly find out how far they can go" T. S. Eliot*

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## LIST OF ABBREVIATIONS

CDA	Critical Discourse Analysis
CDC	Centres for Disease Control and Prevention
CSO	Civil society organisations
CZS	Congenital Zika syndrome
ESPIN	Event in Public Health of National Concern
EVD	Ebola Virus Disease
GBS	Guillain-Barre syndrome
GHN	Global Health Narrative
GHS	Global Health Security
IDS	International development studies
INGO	International Non-Governmental Organisation
MDGs	Millennium Development Goals
PHEIC	Public Health Emergency of International Concern
PRSPs	Poverty Reduction Strategy Papers
SARS	Severe acute respiratory syndrome
SDGs	Sustainable Development Goals
SGBV	Sexual and gender-based violence
SRH	Sexual and reproductive health
UN	United Nations
UN Women	United Nations Women
UNSC	United Nations Security Council
UoA	University of Auckland
WHO	World Health Organization
ZIKV	Zika Virus

## CHAPTER ONE: INTRODUCTION

As COVID-19 sweeps across the globe women's advocacy groups, academics, national and international bodies, such as the World Health Organisation (WHO) and CARE International (herein CARE), are urging governments and development actors to consider the adverse impacts COVID-19 may have on marginalised women and girls (CARE, 2021; Gausman and Langer, 2020; International Labour Organization, 2020; UN Women, 2020; Wenham, Smith and Morgan, 2020; WHO, 2020a). The growing concern around COVID-19 and women recalls historical studies of Zika, Ebola and HIV/AIDS which reveal complex health crises are not gender neutral and women and girls often bear the burden including the exacerbation of pre-existing gender inequalities. They are more likely to experience increased care burdens, income losses due to tenuous work conditions, sexual and gender-based violence (SGBV), reduced and/or a total loss of sexual and reproductive health (SRH) services and stigma (Akande, 2010; Harman, 2011; Harman, 2016; Smith, 2019; Wenham, Smith, Davies, Feng, Grépin, Harman, Herten-Crabb and Morgan, 2020). While there are many reasons given for the exacerbation of gender inequalities, including, cultural, social and familial expectations around women's gendered roles, especially that of caregiving, studies suggest a notable amount can be attributed to the ways in which powerful global health organisations and NGOs deal with disease. Broadly speaking, the ways in which women experience disease, health policy, interventions and outcomes can be understood as the feminisation of health (FOH) being the implicit and/or explicit gendered problematisation of disease (Anderson and Beresford, 2016; Davies and Bennett, 2016; Gupta, Betron, Brown, and Morgan, 2020; Harman, 2011; Harman, 2016; Smith, 2019). The gendered problematisation of health can be partly attributed to the kinds of narratives embedded in global health and how these construct disease and disease affected people in particular kinds of ways. Wald (2008) and Development Studies scholars Dry and Leach (2010) are aware of this problem and have responded by identifying two kinds of narratives which construct disease and affected people in often harmful ways, the 'outbreak' narrative and 'dominant' narratives.

Leach and Dry (2010) and Wald (2008) argue that these two narratives are harmful because they favour western orientated, scientific and medicalised understandings of disease which subsequently inform global interventions. Moreover, they can marginalise or render invisible other ways of thinking about disease, including those of people directly affected or those with worldviews comprised of other kinds of knowledge (Leach and Dry, 2010). Leach and Dry (2010) argue that such 'alternative' narratives offer different ways of thinking about and responding to disease which sit outside of global health narratives. The problem is how to

transform or moderate powerful narratives so that 'alternative' narratives can counteract the FOH and the entrenched views of women in health crises, including the latest one.

This study begins to address this problem by mapping the narratives and response pathways around three contemporary epidemics of the 21<sup>st</sup> century, Ebola, Zika and HIV/AIDS epidemic to discover how they are dealt with by the premier global health agency, the WHO, and an international non-government agency (INGO) CARE. This mapping will provide insights into how particular narratives shape policy responses. The purpose of the thesis is to provide insights into the ways in which power dynamics, ideologies and knowledge production construct disease and shape interventions, specifically those that affect marginalised women in the Global South. It then considers how power dynamics, ideologies and knowledge production within global health may lead to the feminisation of health and the implications this has for achieving gender equality during health crises.

In this thesis I argue that the ways in which global health agencies deal with disease and women exacerbates gender inequality because their stories construct subjectivities without agency. I argue that narratives of disease are foremostly stories about people which shape how disease and affected people are thought about and responded to. I show that contrary to the conceptual framework, there are no safe stories. I argue that 'outbreak', 'dominant' and even 'alternative' narratives or stories of disease cause harm because they are controlled and told by those in positions of power and authority. I argue that these stories are particularly injurious for marginalised women because of the way in which women's experiences are leveraged to reinforce, justify and legitimise Western orientated global health agendas.

The aim of this research is to understand the relationship between global health actors and the stories they tell about disease and women and how this in turn exacerbates gender inequality which contributes to the feminisation of health. To answer this, I am guided by the following overall research question:

In what ways do disease narratives construct contemporary epidemics and the responses? What alternative narratives are marginalised, and what are the implications for women at the margins of society when health is feminised?

#### *Sub-questions*

1. What kinds of narratives and response pathways were utilised by the WHO and CARE International between 2010-2018 and what alternative narratives were marginalised?
2. To what extent are outbreak and dominant narratives embedded in contemporary epidemics and what are the implications for public health?

3. What is the 'feminisation of health', how is it constructed and what are the underlying assumptions about women?

For many researchers including myself, COVID-19 made field research and primary data collection impossible. My original plans were to examine the feminisation of health by focussing on menstrual health issues in Papua New Guinea, including 4-weeks talking with women in Goroka, but in light of the COVID-19 global health crisis, I was forced to re-evaluate my plans. Weighing up my options, I made a timely and pragmatic decision, in consultation with my supervisor, to pivot and adapt my research to accommodate the rapidly changing health crisis. This new research project emerged from close engagement with literature that underpinned my planned field-based study but required a rapid shift to new desk-based methodologies. In undertaking this policy related desktop research, in addition to substantive discussions around the impact of narratives on the FOH, I seek to show that robust desktop research using high-quality secondary data provides useful insights into critical issues. Moreover, it is perhaps now, more than ever, a viable way to do research. It is my hope that this research shows the value of robust policy related research based on secondary data and that engaging with secondary data in a critical way can yield valuable and insightful research.

#### 1.1 Methods, positionality and theoretical approach – an overview

This research uses qualitative research methods to answer the research questions. It aligns with Braun and Clarke's (2019) assertion that qualitative research seeks to understand meaning and how that is achieved within contextual parameters. It also follows their method in which the researcher is flexible in their approach and is an active participant in the research. It also uses critical discourse analysis (CDA) following Fairclough (2011) and Ziaei (2015) who assert discourse analysis has been successfully used to interrogate discourses of underdevelopment, specifically around relations of power. CDA seeks to expose these underlying aspects of discourse through exposure and critical analysis with the goal of evoking change. Due to the use of secondary data, this research required a robust methodological approach. I chose to follow Wodak and Meyer's (2009) systematic data criteria approach which sets specific boundaries around data collection to both provide robust data collection and analysis and to answer the criticisms levelled at CDA.

As an active researcher I recognise my positionality as a Western woman living in the Global North. My perspective underpins this research and is informed by my identity as a Western woman, my unique life experiences and my background in development studies and anthropology. Following Harman's (2020) lead, I acknowledge that in conducting and writing this research I am also a storyteller, reproducing and communicating stories about other people. Harman (2020) raises the question of ethics and rightly asks, "who

has the right to tell, use, and consume stories” (p. 777). As such, I am aware that in reproducing the stories about people and women in this thesis, I am also shaping how people are thought about.

Theoretically, this research draws on the concepts of dominant narratives, narratives and pathways and gender to inform my analytical framework. The concept of narratives provides a way to identify and understand how global health actors deal with disease. It helps expose the ways in which they frame disease, the kinds of knowledge that is preferred and how this constructs diseases which in turn informs the response. The concept of gender is highly contested yet a gender perspective over health and disease is imperative in illustrating how gender and women are dealt with in global health and the implications therein. Gender provides nuance missing in the narratives approach, in particular it asks us to consider the many intersections between gender, women, disease and global health. In terms of this research, it provides a way to identify and understand how global health deals with women and the implications.

### 1.2 Gender, women and global health – an overview

The relationship between gender, women and global health is complex and a source of ongoing tensions. Many scholars and those working in health have highlighted time and again that gender and women are missing in the data, policy and programmes (Harman, 2011; Harman, 2016; Harman, 2020, Smith, 2019). The lack of gender analysis in relation to communicable disease is evident in high-level policies which do not account for gender issues of inequality and discrimination, leaving women exposed to harm (Davies and Bennett, 2016; Smith, 2019). Moreover, when gender is considered, it often results in women being added to governance bodies as a way to deal with the problem of gender inequality and disease (Harman, 2011). Problematically, this is usually a meaningless, powerless inclusion which elicits no positive outcomes for women. It also exacerbates gender inequality through reinforcing women’s reproductive role of caregiver as they are only given space for this voice (Harman, 2011). This research explores this relationship through a gender perspective and focuses on the ways in which gender and women have been instrumentalised in the prevention, management and containment of disease.

In this study I focus on two agencies in positions of power, the global health organisation the World Health Organisation (WHO) and INGO CARE International.

### 1.3 The WHO and CARE International: An overview

#### *The WHO*

Established in 1948, Kamradt-Scott (2016) describes the WHO as being the premier global health organisation mandated with “improving the health of all populations worldwide” (p. 402). A core function of the WHO is the “containment and eradication of infectious diseases” which he suggests “imbued [them] with considerable

authority and autonomy to pursue this goal” (p. 402). He goes on to explain that the “postwar world-view” located health as a “precondition for international peace and security” (p. 401). He also claims that during the early 2000s the secretariat of the WHO “promoted its ability to manage global health security” signalling a shift from its core function, to one that focuses on global health security (GHS).

In terms of epidemic management, the WHO (2018, p. 214) define their role as encompassing the following.

1. Providing leadership on matters critical to health and engaging in partnerships where joint action is needed.
2. Shaping the research agenda and stimulating the generation, translation and dissemination of valuable knowledge.
3. Setting norms and standards and promoting and monitoring their implementation.
4. Articulating ethical and evidence-based policy options.
5. Providing technical support, catalysing change, and building sustainable institutional capacity.
6. Monitoring the health situation and assessing health trends.

According to the WHO (2018), epidemics are increasing in both frequency and global reach; attributable to “globalization, the intense mobility of human populations, (...) relentless urbanization” and “biological, environmental and lifestyle changes” (pp. 11-18). Epidemics are thought to be either a re-emergence of “pathogens that have been familiar for a long time” or “newly-emerging ones” (p. 19). The WHO (2018) describe disease pathogens as a “daunting array of species of bacteria, viruses, fungi and parasites” which infect humans via various vectors including (but not limited to) contaminated water, food and air, human to human contact, and animal and insect bites and stings (p. 19).

### *CARE*

CARE is an international secular humanitarian INGO focused on addressing gender inequality for women and girls. Established in 1945, CARE “works around the globe to save lives, defeat poverty and achieve social justice” through a set of programme principles (see below) (CARE, n.d).

1. Promote empowerment
2. Work in partnership with others
3. Ensure accountability and promote responsibility
4. Address discrimination
5. Promote the non-violent resolution of conflicts
6. Seek sustainable results

CARE identifies poverty and social injustice as fundamental problems affecting women and girls globally.

At its root, poverty is caused by unequal power relations that result in inequitable distribution of resources and opportunities between women and men, between powerholders and marginalised communities and between countries. Poverty cannot be overcome without addressing these underlying power imbalances (CARE, n.d).

#### 1.4 Thesis structure

Chapter one introduces the topic of this thesis, the research questions, and provides brief overviews of the context of the research, the methodology and the theoretical framework. Chapter two introduces the conceptual framework guiding this research. Starting with a discussion around the concept of outbreak narratives, it then considers a narratives and pathways approach. It suggests that together these concepts provide a research framework which helps identify and understand how gender inequality is exacerbated through the way's epidemics are thought about and responded to. It concludes by suggesting that the lack of a gender dimension within these concepts requires deeper thinking about how to address this blind spot. Chapter three introduces a gender dimension to the conceptual framework, highlighting the value of and need for a gender dimension across disease. It does this through illustrating some of the intersections between gender, women and health by engaging with the concepts of the feminisation of responsibility and the ways in which global health has dealt with gender and women. The next chapter introduces my method and research approach, beginning with a discussion of critical discourse analysis, thematic analysis and the use of secondary data including the benefits and constraints. It finishes with a brief discussion outlining my positionality. Ebola, Zika and HIV/AIDS are the focus of chapter five. The purpose of examining these contemporary epidemics is to provide a broad and descriptive overview, specifically around their unique pathogenesis, clinical presentation and historical context. It also establishes an understanding of the unique attributes and challenges around these three epidemics as a forerunner to analysis chapters six and seven which analyses the data in relation to these particular diseases. Chapter six describes the relationship between global health actors and the stories they construct about disease and people. I consider how these stories are constructed and the implications they have for disease affected people. The following chapter explores two fundamental ways that global health deals with disease and women resulting in the gendered problematisation of disease. In the final chapter I consider my research questions and findings. I identify the limitations of this research and provide some thoughts on a way forward towards dealing with and advancing gender equality issues within global health.



## CHAPTER TWO: CONCEPTUAL FRAMEWORK

### 2.0 Introduction

The growing concern around COVID-19 and women's experiences of the pandemic, recalls historical studies of Zika, Ebola and HIV/AIDS which reveal that epidemics are not gender neutral; marginalised women and girls in the Global South often bear the burden, experiencing communicable disease outbreaks differently and disproportionately, compared to men's experiences (Akande, 2010; Harman, 2011; Harman, 2016; Harman, 2020; Smith, 2019). There are many reasons given for this, including, women's biomedical and physiological vulnerabilities to disease (Harman, 2011), socioeconomic factors, the female centric care economy (Anderson and Beresford, 2016), and a lack of sexual and reproductive health (SRH) rights, (Birks, Powell and Hatfield, 2016; Davies and Bennett, 2016; Diniz, 2017; Diniz et al., 2020; Harman, 2016; Smith, 2019; United Nations Population Fund, 2020; Wenham, Smith and Morgan, 2020; Wenham, Smith, Davies, Feng, Grépin, Harman, Herten-Crabb and Morgan, 2020). More broadly, these reasons raise the issue of the feminisation of responsibility and obligation (Chant, 2008). While epidemics do not create gender inequalities, they certainly exacerbate them.

Gender inequality is exacerbated when epidemic planning and responses fail to consider women's experiences of disease, including difference and diversity amongst women both socially, culturally and across geographic contexts. This is reflected in the overwhelming lack of sex-disaggregated data which obscures and homogenises women's roles and experiences (Benelli, Mazurana and Walker, 2012; Harman 2016; Nkangu, Olatunde and Yaya, 2017; Smith, 2019; Wenham, Smith, Davies, Feng, Grépin, Harman, Herten-Crabb, and Morgan, 2020). Further, while global health sees the gendered care role women perform in health, and the disproportionate effects of disease on women, they remain "invisible in global health strategy, policy or practice", except for a few women who occupy high profile health governance positions (Harman, 2016, p. 524). Harman (2016) refers to this as a "central paradox in global health governance; the conspicuous invisibility of women and gender" (p. 524). Although women are largely invisible in global health, epidemic responses instrumentalise women and their gendered roles, locating them as 'agents of change' to prevent and manage disease (Batchold, 2016). This reflects Harman's (2016) argument that "global health rests on the conspicuous free labour of women in formal and informal care roles" (pp. 524-525). A particularly salient example of this occurred during the 2014-15 Ebola outbreak in Sierra Leone where women's "unpaid labour in the care economy fill[ed] the gaps in the health system", thereby, exacerbating pre-existing care burdens (Anderson and Beresford, 2016, p. 477). Although the exacerbation of women's care burdens is just one-way epidemics exacerbate gender inequality, it is not yet clear that it is the most salient and the most devastating.

As illustrated above, epidemics can exacerbate gender inequality in various ways because epidemic governance and the responses typically fail to consider gender. Or, when they do consider gender, it is in relation to the female centric care economy and how it can help deal with epidemics. One particularly potent aspect of epidemic governance which facilitates this, is the construction of epidemic narratives. Before analysing how agencies in positions of power, such as premier global health organisation the World Health Organisation (WHO) and INGO CARE International, construct and deploy narratives, it is useful to understand how narratives are constructed.

### 2.1 Epidemic narratives and the exacerbation of gender inequality

Narratives which are constructed by, and sit within, organisations such as the WHO are considered potent because they are given unparalleled legitimacy and authority (Leach and Dry, 2010). Imbued with power and authority they “suggest and justify particular kinds of action, strategy and intervention” which can result in detrimental outcomes for marginalised people (Leach, Scoones and Stirling, 2010, p. 370). Importantly, the process of constructing epidemic narratives also constructs people in often unfavourable ways (Leach and Dry, 2010). This is particularly true for women who are simultaneously constructed as, responsible ‘empowered’ agents of change, victims, transmitters of disease, irresponsible, negligent and ignorant (Batchold, 2019; Diniz, 2017; Harman, 2011; Harman, 2016; Smith, 2019). Therefore, identifying and understanding the kinds of epidemic narratives used by agencies like WHO and CARE is important to begin to understand how epidemics might exacerbate gender inequality. There are numerous approaches and ways to help identify narratives, but this research focuses on two closely aligned narratives. First, ‘the outbreak narrative’ as it is understood and articulated by Wald (2008). Second, Leach and Dry’s (2010) ‘dominant narratives and pathways’ approach which builds on Wald’s work. Importantly, Leach and Dry’s approach also considers ‘alternative narratives’ which they identify as being other ways of thinking about and responding to epidemics, distinct from outbreak and dominant narratives. Prior to discussing the conceptual framework, I provide a brief understanding of the disciplinary boundaries of the research problem through situating it within Development Studies broad theoretical positioning, specifically those aspects which apply to this research.

### 2.2 Development Studies and discourse, situating the research

Development Studies includes theoretical approaches that recognise the importance of discourse in constructing ways of knowing and doing and the underlying power relations and ideologies (Escobar 1985, 1992, 1995; Ziai, 2015). Ziai (2015) claims discourse analysts working in Development Studies have successfully pointed out power relations “implicit in the discourse in general” and across six key areas, “naturalization, othering, legitimization, hierarchization, depoliticization and appropriation” (p. 17). Othering

occurs when the “naturalization of the Self enables the problematization of the Other” (Ziai, 2015, p. 9). Escobar (1995) describes Othering as an “infantilization of the Third World” (p. 30). Thereby, locating people who live in the Global South (Third World) as backwards and in need of “tutelage and education” (Ziai, 2015, p. 9). Othering is particularly salient in outbreak and dominant narratives because the process of constructing epidemic narratives also constructs people in often detrimental ways (Wald, 2008; Leach and Dry, 2010). Ziai (2015) suggests that a post-development approach might argue that outbreak and dominant narratives are Eurocentric, colonial, and based on western scientific and medical ideologies and notions of modernity which in turn, classify the Global South as ‘underdeveloped, backwards and deficient’.

### 2.2.1 The global health narrative and power relations

Development Studies literature also identifies a very potent epidemic narrative, the global health narrative (GHN) which embodies characteristics of both the outbreak narrative and dominant narratives. McInnes (2016) argues the global health narrative has come to dominate how epidemics are understood and responded to. As with the outbreak narrative, the global health narrative gains its power, authority and legitimacy through the types of knowledge (predominantly scientific) which construct it and who constructs it. McInnes (2016) suggests the global health narrative has “facilitated an accepted, globally applicable pathway of response to the risk of disease outbreaks based on three elements of surveillance, control (including an epidemiological understanding of the disease) and pharmacological interventions” (p. 387). McInnes (2016), Nunes (2016) and Davies and Rushton’s (2016) critique of the 2014-15 West African Ebola outbreak is one example of the global health narrative and its unpinning power and authority in action. They describe how Ebola went from being a long established, neglected, localised health issue to a global ‘crisis’ which McInnes (2016) criticises as being an ‘unnatural’ shift. He suggests the narrative shift occurred because material factors (deaths and infection rates) meant Ebola now ‘fit’ the increasingly popular and powerful global health narrative. Underpinning this narrative shift were several powerful actors, including the WHO the United Nations (UN) Security Council (UNSC); the “WHO declared the outbreak a Public Health Emergency of International Concern (PHEIC)” and the UNSC “passed Resolution 2177, declaring the outbreak a threat to international peace and security” (McInnes, 2016, p. 381). As such, other ways of thinking about Ebola were thoroughly marginalised by this potent global health narrative. While dominant narratives come in many iterations, as suggested by Leach and Dry, my analysis suggests that the global health narrative is the most salient narrative embedded in WHO policy and to a lesser extent in CARE. I suggest this can be attributed to the increasing focus on perceived ‘security risks’ around communicable disease in an increasingly globalised and interconnected world.

### 2.2.2 Development Studies and gender inequality

Development studies also recognises the importance of gender analysis and uses various approaches to consider the impacts of development on gender. For example, Smith (2019) uses a “critical gender lens informed by gender and development”, specifically a feminist economics approach, to reveal gender inequalities in relation to the 2014-15 Ebola outbreak in Sierra Leone (p. 357). In particular, she considers women’s unpaid roles in the care economy and SRH rights. Smith (2019) explains that “G&D (Gender and Development) literature and practice raises awareness about how gender relations and assumptions shape humanitarian and development policies” including gender blindness (p. 357). Harman (2016) draws on the concept of ‘conspicuous invisibility’ located in the “wider feminist debate on gender blindness in international policy making, care and social reproduction” to illustrate the ways in which gender blindness paradoxically renders women visible and invisible (p. 525). Anderson and Beresford (2016) are concerned with women’s gendered care roles being utilised as a “resource within neoliberal development” in which “their unpaid labour mitigates the impact of Structural Adjustment and they become ‘shock absorbers’ in times of crisis” (p. 477). When women are used as resources in these kinds of ways it is often underpinned by the notion that women need ‘empowerment’ and their ‘human rights’ upheld. Development Studies recognition of the role of discourse and its relationship to power, knowledge, othering and gender inequality makes its broad theoretical positioning relevant to the interrogation of epidemic narratives as they sit within global health organisations and the ways in which they are constructed and exacerbate gender inequality for marginalised women in the Global South.

### 2.3 The outbreak narrative

The ways in which we think about, understand, and respond to epidemics can be largely attributed to the stories that circulate about them (Leach and Dry, 2010). These stories gain power, authority and dominance through the kinds of knowledge that construct them and who gets to tell the stories (Leach and Dry, 2010). One such narrative that dominates global health scholarship and policy is ‘the outbreak narrative’. According to Wald (2008) this narrative was popular during the 1990s filling media, popular fiction and film accounts of communicable disease. According to Wald (2008) the outbreak narrative is influential and has consequences for marginalised people and populations because it can,

disseminate information, (...) affect survival rates and contagion routes (...) promote or mitigate the stigmatizing of individuals, groups, populations, locales (regional and global), behaviors, and lifestyles, and (...) change economies (p. 3).

Therefore, identifying and understanding how narratives are constructed and the implications for affected people is critical. This is particularly important for women because studies have shown epidemics exacerbate

gender inequalities and contribute to the gendered problematisation of health and disease. The latter can be understood as the feminisation of health. The feminisation of health is explored in chapter three through a comprehensive literature review which adds a gender perspective to Wald and Leach and Dry's approaches. The relationship between epidemic narratives and the feminisation of health will be analysed in chapter seven as a way to highlight how epidemic narratives increase gender inequality, in particular women's care burdens, SRH issues, economic burdens, and biological vulnerability.

Wald (2008) asserts 'the outbreak narrative' specifically relates to contemporary epidemic events which followed the identification of HIV in the mid-1980s (p. 3). In characterising the outbreak narrative, she describes it is "an evolving story of disease emergence" buttressed by, "scientific, journalistic, and fictional incarnations" (p. 2). In particular, she identifies a set of characteristics which

in its scientific, journalistic, and fictional incarnations – follows a formulaic plot that begins with the identification of an emerging infection [typically located in the Global South], [and] includes discussion of the global networks throughout which it travels and chronicles the epidemiological work that ends with its containment (p. 2).

Importantly, the outbreak narrative constructs the ways in which disease and epidemics are thought about, understood and responded to, but in gender neutral ways. This is evident in the case of SARS being the "first novel infectious disease epidemic of the 21<sup>st</sup> Century" (Wald, 2008, p. 1).

### 2.3.1 SARS

The emergence of SARS and the issuing of a global alert by the WHO in March 2003, signalled the first example of the outbreak narrative. Wald's (2008) description of the unfolding epidemic characterises the outbreak narrative; "epidemiologists rushed to identify its sources and the means and routes of its transmission, journalists scrambled to inform the public of the danger; and medical researchers laboured to find a cure" (p. 1). Notably, Wald (2008) points out that while "the coronavirus [SARS] was new to medical science" it was not a new scenario (p. 1). The scenario of 'disease emergence' was present in previous epidemics; scientists, medical researchers and journalists drew on these scenarios in an attempt to understand SARS, consequently, shaping how they thought about, and responded to it. The rapid emergence and spread of SARS also raised questions such as, "is this *the coming plague?*" a narrative Wald (2008) describes as being a "species-threatening event forecast by scientists and journalists and dramatized in fiction and film in the closing decades of the twentieth century" (p. 2). Hence, Wald (2008) identifies films such as Wolfgang Petersen's 1995 film *Outbreak* as reinforcing and popularising the outbreak narrative through offering "the audience the visceral experience of the graphic description—and the particular horror—of a person's being liquefied by a

hemorrhagic virus” (p. 29). Consequently, Wald (2008) argues that the outbreak narrative has become normalised in science, media, and the public imagination to the exclusion of alternative narratives which lack the same underpinning power, authority and dramatic appeal. This can be largely attributed to epidemiology’s scientific authority, and the fundamental role it plays in identifying and mapping the source and spread of epidemics (Wald, 2008; Leach and Dry, 2010).

### 2.3.2 Epidemiology and the construction of narratives

Epidemiology is the “cornerstone of the outbreak narrative” due to its scientific authority and mandate to make sense of, and respond to, communicable diseases (Wald, 2008, p. 217). A fundamental feature of epidemiology is identifying the origin and source of disease, mapping its spread and eventual containment. One of the ways epidemiology achieves this is through trying to understand the data and statistical analysis. Consequently, Wald (2008) claims this process “turns an outbreak of communicable disease into a narrative” (p. 19). She also attributes the construction of an epidemiology narrative to a reliance on and reproduction of “assumptions about what constitutes a group or population” and “the definition of pathology and well-being” (Wald, 2008, p. 21). Wald (2008) describes how this process also “imports cultural assumptions”, including assumptions about the connection between disease and the lifestyles and certain behaviours of affected people which are often regarded as dangerous and primitive (p. 21). Problematically, when these assumptions are buttressed by scientific and medical authority and risk assessment they become deeply embedded in epidemic narratives. Narratives constructed on such assumptions can obscure the actual underlying causes of epidemics such as poverty, a lack of infrastructure, ecological degradation and climate change; they can also stigmatise people and exacerbate inequalities. The construction of an epidemic narrative typically begins with the epidemiological hunt for the origin and spread of disease; this usually involves identifying a disease infected individual.

### 2.3.3 Superspreaders, index cases and the hunt for patient zero

One of the most interesting and distinguishing features of the outbreak narrative is the epidemiological hunt for the source and spread of disease; involving the search for, and identification of, ‘index cases’ ‘patient zero’, and ‘superspreaders’ (Wald, 2008). This is where narratives move into the realms of myth and contagion and consequently shape people in often harmful ways (Wald, 2008). Epidemiologists tasked with identifying the source of epidemics such as Ebola often find themselves traversing exotic landscapes to track down patient zero, index cases and superspreaders, all of which makes a potent and compelling narrative. Patient zero, and index cases are those individual/s who are identified as the ‘first known cases’ of an epidemic outbreak. Superspreaders are individuals who often unwittingly spread disease through high viral loads of disease microbes and through travel (Wald, 2008). Consequently, these people are often stigmatized and blamed for

spreading disease and “quickly transformed (...) from victims to agents—and embodiments—of the spreading infection” (Wald, 2008, p. 3). In one example, Wald (2008) describes how SARS was unwittingly spread from China to Singapore by a young flight attendant, who upon arriving, infected her community, resulting in the deaths of her parents and pastor. The media portrayed her as “spewing germs out like teakettles” and made her a “national scapegoat” (Wald, 2008, p. 4). Whilst identifying superspreaders and index cases is important epidemiological work, and crucial in managing the spread of disease, it is also highly problematic.

Identifying superspreaders, index cases and patient zero can lead to the stigmatisation of individuals, groups and entire populations (Wald 2008; Leach and Dry, 2010). Consequently, as the focus narrows in on the individual, other ways of understanding and responding to an epidemic may be marginalised or rendered invisible. Wald provides some insights around the relationship between epidemiology, narratives and the identification of a carrier of communicable disease and the consequences therein, through the historical case of Mary Mallon. Specifically, her transformation via an outbreak narrative from Mary Mallon into ‘Typhoid Mary’; the first known healthy human carrier of communicable disease (Wald, 2008). Significantly, this historical insight introduces a gender dimension which is otherwise missing in Wald’s approach. In so, revealing the ways in which the outbreak narrative may exacerbate gender inequality due to the assumptions made by epidemiologists about gender and disease based on social and cultural assumptions about women and their gendered roles. Not only did the hunt for superspreaders, index cases and healthy human carriers signal an emerging emphasis on scientific knowledge, namely epidemiology, it also “helped to recast public health as [a] national security” issue (Wald, 2008, p. 83). As previously discussed, the increasing concern with epidemics and their impacts on notions of national and global health security (GHS) is reflected in the global health narrative. One of the characteristics of the outbreak narrative and fundamental goal of epidemiology is the containment of communicable disease.

Disease containment reflects a medicalized conceptualisation which focuses on the biomedical and geographical containment of disease (WHO, 2018). Yet as Wald (2008) argues, this concept excludes HIV/AIDS from the outbreak narrative as it “cannot be *contained* in *risk groups* because desire cannot be contained by social classifications” (p. 240). She concludes that based on this alone, HIV/AIDS “cannot be directly incorporated into the mythic dimensions of communicable-disease outbreak narratives” (Wald, 2008, p. 27). This raises an interesting question, can epidemics ever really be ‘contained’ when the social and economic implications are profound and long reaching, often lasting much longer than the disease outbreak itself? While depictions of disease containment feature strongly in fiction and film, of which Wald points to many examples, it is, as she suggests, unrealistic.

#### 2.3.4 Criticisms of Wald's approach

Wald's approach is useful, yet it is a lengthy and complex approach which oscillates between fiction and non-fiction, pop-culture and classic literature, making it hard to follow and apply at times. She also lacks a nuanced discussion around alternative narratives and how these might offer other ways of thinking about and responding to communicable disease. Pilsch (2008) alludes to this arguing that Wald is overtly critical of epidemiology and global health processes and fails to see the "possibility of manifesting a global response and compassion for the individual sufferers of disease and the conditions of abject poverty that produce these sicknesses" (p. 327). Wald seems ready to throw out the outbreak narrative and its processes irrespective of the fact that many of these are necessary and beneficial in dealing with disease. This creates a tension between Wald (2008) and Leach and Dry (2010) who argue that "there is nothing inherently 'wrong' with this [outbreak] narrative (both in terms of problem diagnosis and solutions), and there are many merits to the sort of response infrastructure that has been built" (p. 15). This tension is reflected in the data analysis because it is inconceivable that an epidemic narrative or response would not include characteristics of the outbreak narrative, namely epidemiology.

Wald (2008) also fails to consider other cultural perspectives and how narratives are used and expressed in different ways, these are typically understood as alternative narratives. This is reflected in her lack of acknowledgement as to how and "why (...) [outbreak] narratives came into being" (Pilsch, 2008, p. 328). Pilsch (2008) also suggests Wald's approach is strange because it is entirely focused on "twentieth-century American public policy discourse" when her concern lies with the "global nature of contemporary disease practice", arguing it only "moves beyond America in the last chapter, on the AIDS pandemic" (p. 327). He goes on to suggest that this makes her call to change global health narratives hollow. Wald also fails to adequately consider gender in her approach. While she does reveal a gendered dimension in the case of Mary Mallon illustrating the relationship between narratives, gender, and epidemiology, this is a uniquely American experience which does not easily fit the experience or unique contextual spaces of marginalised women in the Global South who suffer gender inequalities profoundly.

#### 2.3.5 The value of Wald's approach

Wald provides a useful way of identifying one particular type of epidemic narrative, 'the outbreak narrative'. Her discussion of the outbreak narrative, and its characteristics, reveals that epidemics are more than biological events; they are constructed and maintained by powerful actors with often detrimental effects on marginalised and affected people. Wald's discussion of epidemiology and its role in constructing the outbreak narrative is useful because it reveals the fundamental role epidemiology plays in constructing the outbreak narrative. Specifically, how epidemiology is more than data and statistical analysis, it is also a compelling and



powerful storyteller supported by scientific authority with the ability to shape how epidemics are thought about and responded to. We clearly see in Wald's framework the power of scientific knowledge, authority and the epidemiological narrative coming together, to not only construct epidemics and their responses but also construct affected people. Epidemiology's prominence, authority and mandate to understand and respond to epidemics means that epidemiology narratives will likely be ubiquitous and explicit in the data generated, especially in that of the WHO.

## 2.4 Dominant narratives and pathways approach

Like the outbreak narrative, dominant narratives are more than just stories, they have consequences. Leach and Dry (2010) argue "a disproportionate amount of (...) [the] burden sits squarely on the shoulders of the world's poorest people" (p. 3). Like Wald (2008), they also argue that dominant narratives exclude alternative narratives and construct people in often harmful ways. Therefore, understanding disease narratives and the power and authority which constructs and maintains their dominance is crucial to addressing how they may exacerbate stigma and inequality. Dry and Leach (2010) build on Wald's approach by suggesting that there are many variations of the outbreak narrative which they refer to as 'dominant narratives'; examples include, Ebola's 'global' narrative, SARS 'scientific' narrative, Tuberculosis "security narrative" and avian influenzas "cluster of dominant outbreak narratives" which focus on "risk management and top-down surveillance" (p. 246). They describe the mechanisms that construct these narratives as clusters of cross-cutting themes including, disease exceptionalism, myths of the local and global and the shaping of narratives and their shaping effect. Notably, they argue that the 'primary function' of a dominant narrative is to maintain global health security. This reflects Wald's (2008) assertion that the identification of healthy human carriers of disease "helped to recast public health as [a] national security" concern (p. 83). Global health security (GHS) has also been identified by Development Studies scholars as a dominant epidemic narrative (Kamradt-Scott, 2016; McInnes, 2016) which sits within the broader global health narrative.

### 2.4.1 The global health narrative and global health security

McInnes (2016), Nunes (2016), Davies and Rushton (2016) and Wenham (2016) suggest that the global health narrative which emerged in the early 21st Century, is the dominant frame through which epidemics are understood. McInnes (2016) describes the global health narrative as consisting of three key themes "which may be broadly characterised as globalisation, securitisation and politicisation" (pp. 391-392). Globalisation refers to processes which enable infectious disease to spread easily across borders and the "allocation and movement of health resources" (McInnes, 2016, p. 384). He argues globalisation has "assisted in the standardisation of disease identification and responses" of which he credits Wald's outbreak narrative as

establishing “a common understanding of and response to disease outbreaks” (McInnes, 2016, p. 384). Politicisation refers to the increased role politics plays in global health. Specifically, around the use and mobilisation of resources in relation to aid and how they are “distributed (..) to organisations or authorities that comply with political agendas, such as good governance and pro-life policies” (McInnes, 2016, p. 385). Moreover, it refers to the relationship between “health developments in low-income countries, including those in Africa, [and how this] affect[s] the interests of high-income countries” (McInnes, 2016, p. 385). Securitisation is about risk. Wenham (2016) claims this has seen “the framing of disease as a security threat in recent decades” (p. 442). There are many reasons why health may be framed as a ‘security threat’. McInnes (2016) offers some explanations which include a growing concern that health crisis can lead to state failure, impacting “regional stability and global security” and the potential for disease pathogens to be used as bioterrorism weapons (p. 384). Though these are important to consider, McInnes finds the most common security concern centres on communicable diseases and the implications therein. Specifically, their ability (actual or perceived) to destabilise economies and regional stability through “worker absenteeism, migration, travel restrictions and reduced investment, at a time when economies were more interdependent than ever before” (p. 385). Global health security is therefore intrinsically tied to processes of globalisation, in that, outbreaks in the Global South can now impact the Global North as never before, threatening health and economies. Preventing such perceived threats from materialising involves collective responsibility and thinking about health security in terms of globally shared responsibility (Wenham, 2016). Wenham (2016) claims this notion is explicit in the WHO, who articulate health as a shared responsibility, involving the “collective defence against transnational threats” (p. 437). The global health narrative is a potent narrative imbued with power and authority which can be understood as a dominant narrative. As previously discussed, dominant narratives are constructed through various processes including disease exceptionalism.

#### 2.4.2 Disease exceptionalism, global health governance and the global health narrative

Labelling a disease ‘exceptional’ conveys a “perception of both urgency and the potential for a relatively quick response” (Dry and Leach, 2010, p. 244). The ensuing exceptional disease narrative is used to justify the “mobilization of vast scientific and policy resources and infrastructures”, resulting in “unusual and especially forceful” rapid and broad responses which focus on “short-term emergency-oriented solutions” (Dry and Leach, 2010, p. 240). In one such example, Ebola was labelled an ‘exceptional’ disease due to its “infectiousness and its virulence”, high mortality rates, and terrible death which made it “exceptionally frightening” (p. 241). The exceptional disease narrative around Ebola justified a rapid and broad response which saw affected people in Africa given “untested vaccines and anti-virals” which raised “ethical questions over the risks involved as well

as political unease over Africa being used as a 'laboratory' for Western pharmaceuticals" (McInnes, 2016, p. 388). Dry and Leach (2010) suggest this kind of approach to epidemic management is popular in global health because it is quick and easy to mobilize. Whilst this kind of response is arguably necessary in some instances, it lacks a long-term health perspective, including alternative ways of responding to disease and dealing with affected people in ways that don't cause harm. Importantly, the exceptional disease narrative sits within and is maintained by the global health narrative and its governance machinery.

Global health governance broadly refers to the "political, and institutional processes, including those involving knowledge and power" (Leach, Scoones, and Stirling, 2010, p. 370). Wenham (2016) describes how the "framework of global disease governance involves many actors, each maintaining an important position in a multi-actor mosaic" (p. 437). However, governance alone does not consolidate power into certain narratives and responses, such as the global health narrative, it is the 'appearance' of consensus among powerful global health actors, such as states, the UN and World Bank, NGOs, the private sector and public-private partnerships to name a few that achieve this (Leach and Dry, 2010; Wenham, 2016). Further, the notion of 'shared responsibility' helps achieve the appearance of consensus (Leach and Dry, 2010). As a major actor in global health governance the WHO (n.d as cited in Wenham, 2016, p. 437) advocates for shared responsibility, stating that "in the 21st century, health is a shared responsibility, involving...collective defence against transnational threats". The appearance of "consensus about the risks of global outbreaks" together with the notion of 'global shared responsibility' legitimises the global health narrative and the responses therein (Leach and Dry, 2010, p. 3).

While consensus is arguably critical in developing and delivering robust, effective policy and responses, Leach and Dry (2010), claim the assumptions underpinning it are counterproductive to the "goal of creating a more equitable and just world for the long term" (p. 3). Moreover, they claim superficial consensus also conceals the self-orientated interests of governance actors. It also marginalises alternative narratives because it is established on "a narrow set of implicit assumptions about epidemics" which in turn support narrow response pathways (p. 3). Inevitably, this results in response pathways that are short-sighted and lack "attention to vital longer term, less controllable dynamics, as well as issues of justice and distribution" (Leach, Scoones and Stirling, 2010, p. 370). Another key mechanism which Dry and Leach (2010) claim constructs dominant and alternative narratives are myths of the global and local.

### 2.4.3 Myths of the global and local

#### *Global myths and dominant narratives*

Dry and Leach (2010) describe how epidemics are typically framed as being either global or local, and note that within these binary frames, opposing myths exist being different sides of the same coin. They argue that whilst this framing has been criticised, attempts to bridge these binary concepts has largely failed. Global myths typically populate the outbreak narrative and dominant narratives. They are rooted in Western “biomedical and techno-scientific tools” such as, “surveillance, drugs [and] vaccines” which are routinely used by global health actors like the WHO (Leach and Dry, 2010, p. 246). The global myth is based on the notion that Western science and medicine is modern and superior, and therefore, better equipped to deal with epidemics. Yet, they suggest that the global myth also manifests as, “climate change, the global financial crisis, terrorism and pandemic disease” (p. 246). This opposition within the global frame occurs because the same modernisation that elevates and favours Western approaches to global health crises such as epidemics, also creates a “unique contemporary vulnerability to novel threats that have the potential to create unprecedented systemic failures at the global level” (p. 247). In other words, the same narratives processes which construct Western modernity as the best way to deal with diseases, reflected in outbreak and dominant narratives, also creates the conditions for epidemics to take hold in the first instance. Thereby, creating tensions within and between narratives. Tensions around narratives make conceptualising and using the concept challenging, which is what I found in my analysis. These tensions are articulated by Leach and Dry (2010) who argue that

the interactions between different narratives and the practices linked to them may involve convergence, complementarity, contestation, overt clashes, hard choices and trade-offs, or even a drama of dominance and resistance – as sometimes occurred (p. 15).

#### *Local myths and alternative narratives*

Local myths typically reflect an alternative narrative about disease. Dry and Leach (2010) identified two opposing local myths amongst their case studies which they claim contrast the dangers of globalization. The first local myth suggests that communities live “in balance with a disease ecosystem through a combination of cultural and ecological adaptations developed over a long-time frame” (p. 247). For example, they describe how communities affected by both Ebola and Lassa fever lived with and managed these diseases using cultural practices developed over time. For these communities, Ebola and Lassa fever are not ‘outbreaks’, they are “part of the fabric of life – albeit a hard life – in a given community, claiming lives occasionally before subsiding once more into quiescence” (Dry and Leach, 2010, p. 247). This is a very different way of understanding and responding to disease; “no more troubling than the occasional thunderstorm” in which communities have come

to accept the uncertain nature of disease as part of life. Problematically, Dry and Leach (2010) suggest that this kind of narrative ignores the “potential for systemic effects resulting from such outbreaks” (p. 247).

On the other hand, the second local myth portrays “communities flexibly adapting to change” through long established robustness and resilience; based on traditional knowledge around “flora and fauna” and “agricultural, economic and social needs and [the] realities of people living in an area subject to outbreaks” (Dry and Leach, 2010, p. 247). What we see in these two local myths are alternative ways of thinking about and responding to communicable disease. These can be understood as alternative narratives. When dominant narratives such as the outbreak and global health narratives persist, alternative narratives are marginalised and the opportunity to add complexity and nuance to the global health response is missed.

Alternative narratives are typically context specific and provide on-the-ground complexity which is missing in dominant narratives. Dominant narratives often exclude alternative narratives and responses, including, the “account [of] neglected perspectives, and neglected people” “local knowledge, ecology, history and social sciences”, and the “multi-scale interactions between disease, ecology, society and politics” (Leach and Dry, 2010, p. 5). For example, the outbreak narrative located swine flu as a global epidemic resulting in the rapid scale up of existing H5N1 pandemic response measures yet Leach and Dry (2010) claim an alternative narrative exists in Mexico which considers swine flu

a much longer-established pig influenza, and of the political economy of highly industrialized, intensive pork production methods and worker conditions which may have enabled its spread and species jump (p. 1).

In another example, Leach and Dry (2010) point to alternative narratives which framed “H1N1 as a relatively mild influenza, with much in common with regular seasonal influenzas” and thus can be medically treated in the same ways (p. 1). Here we see two examples of alternative narratives which suggest different ways of thinking about and responding to epidemics.

Unlike alternative narratives, dominant narratives collapse complexity by leaving out the “chronic, the endemic and the entrenched: the flipside of the exciting, if unnerving image of a fast-moving, interconnected globe that animates many outbreak narratives” (Leach and Dry, 2010, p. 8). This speaks to Wald’s (2008) assertion that epidemiology narratives are potent because they are ‘brilliant detective stories’ of disease. It could be suggested that one of the reasons alternative narratives remain marginalised is because they have no dramatic appeal to western audiences, are considered ‘folksy’ and mired in ‘unsophisticated’, ‘uneducated’ thinking.

However, when alternative narratives are exposed, they reveal that “disease is subject to a range of understandings, or narratives, with more on-the-ground complexity than a global outbreak narrative can capture” (Leach and Dry, 2010, p. 8). Importantly, both Wald (2008) and Dry and Leach’s (2010) approaches show that narratives not only construct epidemics, they also construct disease affected people.

#### 2.4.4 Constructing people

Leach and Dry (2010) argue that the process of constructing diseases also constructs “people and populations, labelling and making moral judgements about them” (p. 5). For example, they claim outbreak and dominant narratives often draw on “colonial assumptions about the backward, insanitary customs and lifestyles of poorer African and Asian populations that motivated often coercive public health campaigns in the early 20th century” (p. 5). In other words, people and populations who suffer epidemics are ‘othered’ and blamed for the outbreak based on assumptions about their living conditions and cultural practices. For example, studies of Ebola and Zika found that outbreak narratives stigmatised affected individuals, groups and populations through often contradictory narratives and responses that both blamed women for the spread of disease while also constructing them as agents of change in the battle to contain it (Harman, 2016; Diniz, 2017). In chapter three I elaborate on the ways in which women are constructed through dominant narratives, in particular I discuss the case of Mary Mallon who was portrayed as an immoral woman and vilified as the source and spreader of the typhoid outbreaks in the early 1900’s. The case of Mary Mallon presents a historically relevant example illustrating how disease narratives can exacerbate gender inequality through constructing women in particular ways.

#### 2.4.5 Processes and pressures that shape and maintain dominant narratives

Key pressures and processes shape and maintain dominant narratives, these include political-economic interests and institutional, disciplinary and cognitive pressures which may “interlock in processes of governmentality” (Leach and Dry, 2010, p. 250). Together, these processes and pressures, along with diffuse power relations, mean dominant narratives typically go unchallenged. Political-economic interests, specifically funding, is a powerful instrument that not only shapes but also maintains dominant narratives (Leach and Dry, 2010). Dry and Leach (2010) describe institutional pressures as being concerned with ensuring an ‘institutional fit’ between agencies such as the WHO and the global outbreak narrative. Essentially, there is an expectation that the narrative and the agency are compatible, and alternative narratives are not seen as compatible, and are therefore marginalised and/or rendered invisible. Whilst professional, disciplinary and cognitive pressures shape narratives through power dynamics. These pressures construct dominant narratives through their strong emphasis on scientific knowledge, including, biomedicine, epidemiology and the ensuing quantitative

assessments. Whilst scientific knowledge is critical in understanding and responding to epidemics it is not the only way epidemics can be thought about. Dry and Leach (2010) suggest epidemics can also be understood through the disciplines of ecology, social science and history. These disciplines reveal and promote alternative narratives which locate epidemics within the context of social, ecological and technological processes, including increases in population and domesticated animals, environmental and land use changes, climate change and technologies such as drugs and vaccines and their effects (Dry and Leach, 2010).

## 2.5 Conclusion

Leach and Dry's approach provides a way to understand why certain narratives dominate and persist within the global health machinery. They do this through revealing the complex relationship between narratives, governance, global health security, the global health narrative and power relations. Importantly, they reveal how response pathways are based on narrow assumptions about people and disease which gain strength and legitimacy through the appearance of consensus amongst powerful global health actors. In turn, these can marginalise alternative narratives which typically take a long-term, contextual view of epidemics. This thesis analyses the discourse from WHO and CARE to reveal the extent to which the interdependent relationship between consensus, governance and disease exceptionalism persists with the aim of maintaining global health security at the expense of alternative narratives. I am also interested in how disease exceptionalism and global health security are explicitly and ubiquitously embedded in WHO policy, thereby aligning with their mandate to maintain and reinforce global health security.

It must be noted that Leach and Dry (2010) do not advocate throwing out the outbreak narrative. They argue that "there is nothing inherently 'wrong' with this narrative (both in terms of problem diagnosis and solutions) and there are many merits to the sort of response infrastructure that has been built" (p. 15). However, like Wald (2008), they identify several problems, specifically, the marginalising and/or lack of alternative narratives which can lead to the exacerbation of pre-existing inequalities for marginalised people. This raises a question, should alternative narratives sit alongside or be included in dominant narratives? While making room for alternative narratives has merit, it is still a reactionary approach. It is also unlikely that they would ever command the same authority and power and therefore shape responses in any meaningful way. Unlike dominant narratives, their value lies in their histories, cultural significance, local knowledge, diversity, complexity and contextuality, Therefore, it might be better to take a proactive approach which builds on these narratives to address the issues that the dominant narratives do not, such as, structural inequalities, climate change and ecological destruction. It is these underlying issues that render marginalised people more susceptible to adverse social, biological and economic impacts of epidemics, including the exacerbation of

gender inequality. Finally, although both Wald (2008) and Leach and Dry's (2010) conceptual frameworks are useful in understanding the dominant narratives that construct epidemics and the responses, they fail to consider the feminisation of health. This introduces the question of women; specifically, how do epidemic narratives affect women? These approaches are not well suited to exploring the nuance around gender inequality and epidemics. To answer my research question, what is the feminisation of health, I need to introduce a gender perspective to guide this exploration.



## CHAPTER THREE: THE VALUE OF, AND NEED FOR A GENDER PERSPECTIVE ACROSS DISEASE

*The inequalities of outcome are, by and large, biological reflections of social fault lines*

*(Paul Farmer, 1999, p. 5)*

### 3.0 Introduction

In the previous chapter I introduced the conceptual framework which guides this research and showed how it provides a way of identifying and thinking about the different kinds of disease narratives that sit within global health organisations and NGOs. I showed why this is important for marginalised people and women which studies suggest experience epidemics disproportionately and differentially to men (Harman, 2011; Harman, 2016; Wenham, Smith, Davies, Feng, Grépin, Harman, Herten-Crab, and Morgan, 2020; Smith, 2019). While it is widely accepted that epidemics are not gender neutral, this is not reflected in the ways in which women and their experience of epidemics are thought about or responded to. The purpose of this chapter is to introduce and establish the value of, and need for, a gender perspective across the many intersections of communicable disease, global health and gender which is missing in the conceptual framework.

This chapter is constructed in two parts; part one deals with the relationship between gender and global health. Part two, deals with some of the specific ways women and gender are dealt with, beginning with stories about women and disease and why they matter. I then consider two key areas that are fundamental in shaping women's experience of disease. First, how contemporary disease governance has constructed women. Second, how 'the problem' of disease is dealt with and the implications for gender and women in relation to three contemporary epidemics, Ebola, Zika and HIV/AIDS. Finally, I explore some of the underpinning reasons which lead to the gendered problematisation of disease. In chapter seven I will argue that together, these contribute to what can be understood as the feminisation of health (FOH).

### 3.1 Gender, women, and global health

#### 3.1.1 Conceptualising gender in global health

Conceptualising gender in global health is important because the relationship between gender and health is fundamentally linked. Gupta, et al. (2020) assert that "gender as a construct affects how individuals live and work within society and, therefore, is inextricably linked with the health of that individual" (p. 477). Yet, defining 'gender' is not straightforward and it is often problematic because it is a highly contested concept, academically, politically, culturally, and socially. Some of this is due to the historic substitution of the terms sex and gender; sex refers to the biological attributes of a person while gender refers to the "social construction of behaviors and roles deemed appropriate by society for females, males, and other genders" (Gupta et al., 2020,

p. 476). To clarify my position, I follow the understanding of gender as proposed by Wenham et al. (2020) which they describe as “neither binary nor fixed” (p. 195). Specifically, within the context of global health and communicable disease, I follow their assertion that gender “intersects with other social stratifiers such as ethnicity and race, religion, location, disability and class” and it is therefore affected by numerous relational factors (p. 195). For the purpose of this research, I am focusing on those who identify with a female gender identity and are affected by communicable disease; whilst acknowledging that communicable disease “affects non-binary and transgender people” differently (Wenham et al., p. 195).

### 3.1.2 Global health and how it deals with gender and women

Global health deals with gender and women in particular ways; Harman (2020) claims that “there seems to be an unspoken agreement – demonstrated by the lack of gender analysis in global-level policy documents – that gender is not relevant to global-level processes” (p. 365). This is reflected in Smith’s (2019) argument that there are “global ‘gender gaps’ in policy documents on disease outbreaks” (p. 358). Specifically, she points to a lack of acknowledgement of gender inequality issues and the needs of women in terms of health. Likewise, Payne (2009) identifies gender blindness as a fundamental problem in global health and warns that

health systems that are ‘gender blind’ – that is, where gender differentials in health services are not recognised – may maintain and/or reinforce gender inequalities and gender inequity in wider society, both in their day-to-day operation and in their development of health policies (p. 4).

Davies and Bennett (2016) found that “pre-existing relationships between gender, health and inequalities” were seldom considered during a health crisis (pp. 1045-1046). Notably, they found that while the prevalence of gender inequality and gender discrimination was known, it did not translate into international policy advice. They suggest that, there were too few occasions where international advice appeared to take account of diminished rights and right to access health care when promoting the choices that women, in particular, had to protect themselves and their families (pp. 1045-1046).

Gupta et al. (2020) claim that gender is often overlooked in health because “programmes that target women’s health typically take a biomedical approach” (p. 477). Problematically, biomedical approaches are usually developed on the sex-based differences between men and women and how these shape “health conditions and morbidities for women” (p. 477). Thereby, ignoring the social drivers of disease, such as poverty, structural inequalities, gender inequality, diminished autonomy, inadequate sexual and reproductive health (SRH) care, unstable employment and care burdens. This in turn, leads to programmes which fail to consider the gendered

dimensions of disease and health. Moreover, Gupta et al. (2020) suggest that programmes which focus on health conditions and morbidities tend to target the reproductive roles of women and health often leading to harmful outcomes for women.

### 3.1.3 Targeting SRH

A health-based strategy which targets women's SRH as a way to deal with communicable disease is not uncommon; in some instances, it is necessary, yet it can also be highly problematic and harmful. For example, during the 2015-16 Zika outbreak in Brazil women's SRH was targeted as a way to deal with Zika bringing into focus the numerous pre-existing SRH issues women faced. A turning point in SRH for women at this time was the scientifically established fact that Zika could be both transmitted sexually and vertically from mother-to-foetus via the amniotic fluid (Diniz, 2017). This saw SRH targeted as a way to deal with Zika. Prior to this discovery, the SRH of Brazilian women was woefully addressed (Batchold, 2020; CDC, 2016; Diniz, 2017; Diniz et al., 2020; WHO, 2018). Yet, targeting SRH did not result in improved outcomes for women, it highlighted and exacerbated historic and ongoing SRH inequalities because despite the lack of access to contraception and legal abortions, women were instructed to delay pregnancy for up to 2-years by both national and global health actors (Batchold, 2020; CDC, 2016; Diniz, 2017; Diniz, Ali, Ambrogi, and Brito, 2020; WHO, 2018). The focus on SRH also highlighted inequities in access and care. Diniz (2017) claims poor women were more acutely affected because they lacked access to adequate health care, contraception and abortions and their economic situations meant they could not leave Zika infested areas. Whereas, elite women had the financial means to access contraception, travel to obtain a legal abortion or leave Zika infected areas and continue their pregnancies in other parts of Brazil or leave Brazil (Diniz, 2017; Harris, Silverman, and Marshall, 2016). Essentially, targeting SRH as a way to deal with Zika belies the historic and ongoing issues of equality and equity in Brazil's SRH system. Moreover, it exacerbates SRH inequalities through making women responsible for their SRH when issues of access and autonomy are deeply entrenched.

Furthermore, orientating programmes towards SRH neglects "the health needs of women who fall outside of the reproductive years" (Gupta et al., 2020, p. 476). Similarly, Smith (2019) argues that the

focus on maternal health also obscures the roles and responsibilities of men related to reproductive health, the health needs of women unrelated to reproduction, and of the right to sexual health for people of all genders who cannot or chose not to have children (p. 361).

Smith (2019) also warns that when disease outbreak policies and responses are aligned with SRH care roles, it reinforces "assumptions that women are solely responsible for reproductive and family health" (p. 361). I will

expand on this later when I consider the gendered role of caregiver. Notably, neither Gupta et al. (2020) nor Smith (2019) are diminishing the importance and need for SRH to be addresses in health responses or policies, particularly during disease outbreaks, instead they are highlighting the implications for women and their wellbeing when SRH becomes the primary focus of policy and responses. When SRH becomes the primary focus the social drivers of disease and gender inequality “perpetuate women and girl’s vulnerability and marginalization” (Gupta et al., 2020, pp. 476-477). Failing to consider the gendered aspect of health and disease results in health programmes which neglect to,

- (a) examine unequal social dynamics that interact with women’s physiology to produce poor health outcomes, (b) address the factors underlying women’s subordinate positions in their households, communities, and societies that undermine their health status, and (c) recognize others who share responsibilities and play a role in women’s health decision making (e.g., husbands, in-laws, or other family members) (Gupta et al., p. 477).

Neglecting to consider and include gender in global policies around disease outbreaks “ignores how women, men, and other groups experience outbreaks and responses differently” (Smith, 2019, p. 359). Moreover, Gupta et al. (2020) argue that incorporating “a gender lens into women’s health programming is to address the structural, socio-cultural, or relational dynamics that influence health and health-seeking behavior” (p. 477). It also reveals the power relations at work within global health which inevitably influence the outcomes for women.

### 3.2 Stories and the value of a gender perspective in teasing out their impact on women

Stories impact women in profound ways, often exacerbating gender inequality and stigmas. Particularly, when they are told by others in positions of power and authority within global health. The ways in which global health deals with women and disease can be understood through examining how stories are used and how they impact women.

#### 3.2.1 Stories and global health

Stories are a potent means of communication because they “have long been (...) [used] to explain what is happening to us, to think through our fears, and relate to each other as human beings” (Harman, 2020, p. 777). Within the context of global health, Harman (2020) describes stories as being a “provision of comfort”, a means through which we can think about ourselves, our health, and our place in the world they also breakdown our prejudices and fear through reminding us we share a common humanity (p. 777). Conversely, she warns that stories are “dangerous when they spread false information, (...) impose single narratives, and (...) we think them irrelevant to the work of science, medicine, and global health”, moreover when they are overlooked, and

used to control and vilify people (p. 777). Within the context of global health, who gets to tell the story is highly problematic, controversial and raises ethical questions (Leach and Dry, 2010; Harman, 2020).

Pointing to the ethical issues around stories, Harman (2020) rightly asks, “who has the right to tell, use, and consume stories” (p. 777). In so, she highlights one of the more troubling ways in which stories are used to elicit desired outcomes through inviting the audience to ‘eat the trauma’ of the storyteller. What’s more, she claims this kind of story has been widely and frequently used by “international charities in their fundraising appeals” (p. 777). The trauma typically served up for consumption is that of women, whom I have previously shown experience disease differently and disproportionately to men. Demonstrable in the highly gendered nature of diseases such as Ebola, Zika and HIV/AIDS which are acutely harmful to women, socially, economically, and biologically all of which makes for compelling stories.

#### *Stories, global health and women*

The power of stories to shape how we think about and respond to people and disease is profound, especially for women. Particularly when the ones telling, and thereby, controlling the stories hold positions of power and authority (Leach and Dry, 2010). One of the most potent ways in which powerful global health actors construct stories and invite the audience to ‘eat the trauma’ of the disease-affected victim is through utilising personal testimony. Although Dry and Leach (2010) suggest that stories told by disease-affected people are typically left out of larger disease stories told by global health organisations, I suggest that some stories which centre around women are incorporated into larger stories (or dominant narratives) of disease in the form of personal testimonies. I expected to find the prevalent use of personal testimonies in CARE stories of disease and to a lesser extent in WHO stories. I expect my analysis to show that their presence serves to support and justify donor agendas and interventions, both new and existing.

Unlike personal testimonies which sit within larger stories told by and controlled by powerful actors, there is immense value in the stories told by women which sit outside global health organisations. Women have important and insightful stories to tell from their experiences and knowledge gained working at the fray of many epidemics, including those which highlight how SRH inequalities are exacerbated by disease and interventions (Harman, 2020). It is in these stories that

different understandings (...) may emerge from the experiences, knowledge and perceptions of people living with diseases on a daily basis, or as related to the influence of media, religious or other groupings. How epidemic problems are understood also relates to location, wealth, livelihood,

gender and other factors that shape people's vulnerability both to disease, and to the effects of particular kinds of response (Leach and Dry, 2010, p. 13).

Stories such as these threaten global health actors because they are disruptive often exposing "inconvenient truths for governments and international actors", running contrary to their agendas and narratives, exposing weaknesses in programmes, structural inequalities, donor agendas and different ways of thinking about diseases and responses (Harman, 2020, p. 776). Problematically, ignoring women's stories, their knowledge and experience of disease exacerbates gender inequality and reinforces stigmas. Harman (2020) argues that "too often when we dismiss stories, we dismiss women", she warns that if we do not "listen to these stories [of disease affected people] any intervention to stop the spread of diseases, however scientifically advanced, is likely to fail" (p. 777). Dismissing women's stories also ignores the ways in which disease affected women internalise them, leading to harmful embodied perceptions of their identity. For example, Evans and Atim (2011) describe how HIV positive Tanzania women were so confronted with their diagnosis and the stigma surrounding it that they were

forced (...) to reconsider their lives and their identities [and] several women struggled to reconcile their sense of self with a highly stigmatised health identity, questioning why and how they had become infected (p. 1443).

In chapter seven, I show how global health actors utilise personal testimonies of disease affected women to reinforce, justify and legitimise interventions. I will argue that while such stories ostensibly provide useful insights into women's lived experience, they cause harm through framing women in particular ways, namely powerless victims and 'empowered' and responsible agents of change, thereby exacerbating gender inequality and reinforcing stigmas. I have shown here that stories about women, and told by women, are important to consider. It is also important to consider stories constructed about women in the early years of public health. Wald (2008) highlights two fundamental ways in which women were perceived in early public health. First, they were constructed as 'fallen women' whose so-called deviant behaviour was thought to spread disease, demonstrable in the case of Mary Mallon who was accused of spreading typhoid (Wald, 2008). Second, women were perceived as being irresponsible mothers, who in their gendered roles and responsibilities had failed to keep a home conducive to preventing disease. In chapter seven I will show how these early public health stories about women which explicitly blame them for the spread of disease reveal a change in how women were perceived, first in public health then in global health.

### 3.3 Adding women and gender to the problem: Underpinning explanations

Some of the most salient drivers underpinning the addition of women and gender as a way to deal with health problems include (but are not limited to), the feminisation of poverty and responsibility, western orientated development agendas and neoliberal ideologies (Anderson and Beresford, 2016; Chant, 2016; Harman, 2016; Leach, 2015).

#### 3.3.1 The feminisation of poverty and responsibility

Chant's (2008) insights into the feminisation of poverty provides a way to help understand the feminisation of health. The feminisation of poverty thesis first emerged during the 1970s but wasn't taken up in the "development lexicon until the mid-1990s" when poverty and women featured at 1995 Fourth UN Conference on women (p. 166). This conference both exposed and cemented the relationship between women and poverty when the assertion was made that "70 percent of the world's poor were female" and poverty eradication for women was "adopted as one of the 12 critical areas of the Beijing Platform for Action (BPFA)" (p. 166). Hence, women and gender were linked with poverty reduction; a relationship which was subsequently included in the Poverty Reduction Strategy Papers (PRSPs) and the Millennium Development Goals (MDGs) (Chant, 2008). Chant (2008) suggests that linking women to poverty through the feminisation of poverty thesis has significantly elevated women and led to interventions and resources targeting women in the areas of education, micro-credit, vocational skill enhancement, and economic and infrastructural support to female-headed households. Similarly, Wennerholm (2002) claims the feminisation of poverty thesis has illuminated the "great number of women living in poverty" and "the impact of macro-economic policies on women; and "called for women to be recognised in the development process" (p. 10). Simply put, the feminisation of poverty thesis highlighted the relationship between women and poverty and spurred action on poverty reduction. Whilst the feminisation of poverty has certainly helped advance gender inequality issues, Chant (2008) argues it is not without problems. First, it fails to consider differences among women, for example, a "women's age-related risk of poverty is cross-cut by other factors such as household circumstances, education and employment" (p. 174). Second, it places too much emphasis on income through the "implicit privileging of income" to the exclusion of social and cultural drivers, "access to land and credit, decision-making power, legal rights within the family, vulnerability to violence, and (self) respect and dignity" (p. 174). Third, the problematic focus on female-headed households as determiners of gendered poverty which fails to consider the role of men, the family unit construction, women's agency, differences between households and culture (Harman, 2011). Finally, it misses the major points about gendered poverty, the 'feminisation of responsibility and obligation' (p. 176). The feminisation of responsibility and obligation emerged from Chant's observations during fieldwork in The Gambia, the

Philippines and Costa Rica which lead her to argue that the underlying drivers of poverty need to be considered as much, if not more than, income. This prompted her to call for a re-orientation of the feminisation of poverty thesis. Chant (2008) suggests that while the feminisation of poverty has some merits, it fails to fully capture and “reflect trends in gendered disadvantage among the poor” nor does it “highlight the growing responsibilities and obligations women bear in household survival” (p. 166). Therefore, as she suggests, it is not so much about a ‘feminisation of poverty’ in the conventional sense (being the differential income between men and women) but a ‘feminisation of responsibility and obligation’ (pp. 177-178).

### 3.3.2 The feminisation of responsibility and obligation

Chant (2008) identifies three fundamental factors which inform the feminisation of responsibility and obligation.

1. Diversification and intensification of women’s inputs to household survival versus status or diminution of men.
2. Persistent and/or growing disparities in women’s and men’s capacities to negotiate obligations and entitlements in households.
3. Increasing disarticulation between investments/responsibilities and rewards/rights.

Chant’s (2008) first point alludes to a growing trend in which women’s work burdens are increasing outside the home, including “performing the bulk of unpaid reproductive tasks for husbands, fathers, brothers and sons” (p. 178). Second, the increase in women’s work does not equate to an increase in agency or voice within the home. Third, she raises the lack of synergy between an increase in responsibility around poverty reduction and an increase in rewards and rights. She also argues that the focus on women and poverty alleviation obscures a better “understanding of gendered poverty” (p. 182). Chant’s feminisation of responsibility and obligation provides a critical gender perspective which helps reveal a turn towards the feminisation of care practices in global health. It is in this turn that we begin to see more clearly the parallels between the feminisation of responsibility and obligation and the feminisation of health and how they are intimately related. The underlying problem is how does the relationship between women, gender, SRH roles and global health create a feminisation of health? How does the feminisation of health exacerbate gender inequality in relation to Ebola, Zika and HIV/AIDS and to what extent do neoliberalism and western orientated development agendas play in the feminisation of health?

### 3.3.3 Neoliberalism and western orientated development agendas

The ideology behind adding women and girls into the development discourse as a way to deal with problems in health, is rooted in neoliberalism, Western orientated development agendas for the Global South, and the failed structural adjustment policies (SAPs) of the 1980s which devastated economies and severely weakened



health systems (Anderson and Beresford, 2016; Chant, 2016; Harman, 2016; Leach, 2015). Underpinning this is the increasing role politics plays in global health which McInnes (2016) argues has seen, amongst other things the imposition of ‘aid conditionalities’, “whereby aid resources are distributed only to organisations or authorities that comply with political agendas, such as good governance and pro-life policies” (pp. 391-392). As I will come to show, gender mainstreaming is one such condition. Moreover, it is one of the fundamental drivers behind global health agendas which add women to governance bodies and instrumentalise women’s gender role as caregivers. While aid conditionalities deal with women and gender through gender mainstreaming, neoliberal ideology instrumentalises women and their gendered role of caregiver.

Anderson and Beresford (2016) argue that “women are a resource within neoliberal development: their unpaid labour mitigates the impact of Structural Adjustment and they become ‘shock absorbers’ in times of crisis” (p. 477). The 2007-08 global financial crisis cemented the notion that adding women and girls to a problem was a viable way to deal with it. It was thought that adding women was ‘Smart Economics’ because it would deal with the failures of the SAPs, prevent another crisis, alleviate poverty and address gender inequality (Anderson and Beresford, 2016; Chant, 2016). Essentially, ‘Smart Economics’ “advocates investing in women and girls to reinvigorate economic growth and alleviate poverty” on the premise that “gender inequality is *bad for business*” and females should be ‘empowered’ (Chant, 2016, pp. 314-315). While women and their gendered roles have been instrumentalised in various ways across time to deal with a multitude of problems both locally and globally, it is particularly evident in the female centric care economy where “the burden of care-giving at multiple levels, public and private, is highly feminised” (Harman, 2016, p. 525). As previously illustrated, Chant (2008) provides valuable insights into the way in which practices of care are feminised through the feminisation of responsibility and obligation.

Adding women to health problems occurs for many reasons as illustrated above. These include western orientated development agendas, neoliberal ideology, the feminisation of poverty and responsibility which Chant (2008) claims fixes women to their gendered roles as caregivers which in turn leads to the instrumentalisation of women in global health.

### 3.4 Dealing with the ‘problem’ of disease

#### 3.4.1 Instrumentalising women and gender

While women and their gendered roles have been instrumentalised in various ways to deal with a multitude of problems both locally and globally it is particularly evident in health, through the instrumentalization of the gendered role of caregiver; “the burden of care-giving at multiple levels, public and private, is highly feminised (Harman, 2016, p. 525). It is also evident in health governance. Problematically, Harman (2011) argues that

adding women and gender to health governance disregards structural inequalities which drive gender inequality. As I will show, rather than empowering women, policies which seek to add women and gender roles as a way to deal with health problems harm them through exacerbating gender inequality and reinforcing stigmas. Before that, I show how the gendered role of caregiver has been instrumentalised to deal with the problem of disease and the implications for women across three contemporary epidemics, Ebola, Zika and HIV/AIDS and the implications for women.

### 3.4.2 The caregiver

A women's socially constructed role of caregiver is considered fundamental in the prevention and management of epidemics (Anderson and Beresford, 2020). Demonstrable in the data around women in the care economy which shows that "women represent 70 percent of the health and social sector workforce globally" (The United Nations Population Fund, 2020, p. 1). While some "90% of caregivers for people living with HIV in Africa" were women and girls (Fawole, Bamiselu, Adewuyi, and Nguku, 2016, p. 3). These statistics reveal the magnitude of the gendered health system. It also unequivocally illustrates that women carry the burden of care and that "global health rests on the conspicuous free labour of women in formal and informal care roles" (Harman, 2016, pp. 524-525). Moreover, "it is in the interests of those actors at multiple levels of governance to maintain this care role of women to perform these key functions within the response" (Harman, 2011, p. 221). A striking example of the instrumentalization of women and gender occurred during the 2014-15 Ebola outbreak in Sierra Leone where women's conspicuously invisible "unpaid labour in the care economy fill[ed] the gaps in the health system and women have taken on much of the burden of care in the EVD (Ebola) outbreak" (p. 477). In another example Harman (2011) explains that the "unpaid role of women as carers underpins the core priorities of the global HIV/AIDS response as they are at the forefront of prevention, treatment, and care" (p. 221). The role of caregiver cannot be talked about without first acknowledging the disparities in SRH care and the role this plays in exacerbating care burdens as demonstrated in Brazil during the 2015-16 Zika outbreak.

#### *Care burdens, the inequity of gender inequality in SRH and the impacts on women*

As with many diseases, the most marginalised women in society typically experience acute outcomes in both their care burdens and SRH. Studies of the 2015-16 Zika outbreak in Brazil highlight this revealing a punitive and unjust SRH system which profoundly affected the most marginalised women, due to inequity of care (Bardosh, 2020; Diniz, 2017). Unlike poor women in the North Eastern region of Brazil, women with financial means were able to access contraception, travel out of Brazil to continue their pregnancy in safety or get an abortion (Bardosh, 2020; Harris et al., 2016). Moreover, the Brazilian government compounded this existing inequity through "confiscating international shipments of pills for medical abortion" and seeking to "increase

sentencing minimums for women who obtain abortions for fetal anomalies linked to Zika infection” (Harris et al., 2016, p. 1). The exacerbation of SRH inequity and inequality was not only confined to punitive SRH policies, it was also caused by the Catholic church who vilified and criminalised women (Harris., et al 2016).

The role the Catholic church has in influencing the SRH rights of women in Brazil cannot be overstated. A potent example of this occurred when Pope Francis doubled down on Catholic church doctrine, reaffirming the church’s position that while “avoiding pregnancy is not an absolute evil” abortion is “an absolute evil” and a “crime” (Global Fund for Women, n.d). The reaffirmation of the churches’ position on reproduction rights further cemented the feminisation of Zika and the response therein as predominantly a women’s responsibility with dire consequences. Not only did the church’s position and Brazil’s punitive SRH laws harm women, they were also explicitly targeted and instrumentalised in the ‘war’ against microcephaly and later Congenital Zika Syndrome (CZS) (Ribeiro et al., 2018). Commencing with carrying the reproductive burden of not getting pregnant for up to two-years, through managing their sexual lives (Bardosh, 2020; CDC, 2019). While the church, the Brazilian government and Health Ministry placed the burden of dealing with Zika squarely on women and their SRH, prominent health actors, including the WHO and the Centers for Disease Control and Prevention were also complicit (Ribeiro et al., 2018; Rivera-Amarillo and Camargo, 2020). Subsequently, poor women have endured the greatest care burdens because children with CZS are disproportionately born to women and girls of low socio-economic status.

The inequality of increased care burdens amongst poor women was not confined to mothers, it also impacted other female family members, including grandmothers and aunts who were also burdened with caring for CZS affected children. Like the mothers of CZS children, they also suffer the intensified and ongoing “social and economic burden[s] of the disease” (Batchold, 2020, p. 12). The adverse impacts of which are now well-understood, including “vulnerability to anxiety and depression and deepening poverty” (Lowe, Barcellos, Brasil, Cruz, Honório, Kuper, and Sá Carvalho, 2018, p. 9). Furthermore, anecdotal reports suggest the burden of care was exacerbated because women were frequently abandoned by their partners and largely neglected by the Brazilian Health Ministry (Batchold, 2020; Diniz, 2017; Ribeiro et al., 2018; Smith, 2018; Global Fund for Women. n.d).

The disproportional female centric care economy born out of culturally and socially gendered roles and expectations is just one aspect of epidemics that can exacerbate what can be understood as the feminisation of health. It is also well understood that caring for sick family members or the wider community significantly

increases a women's risk of transmission to some communicable diseases (Diniz, 2017; Diniz et al., 2020; Evans and Atim, 2011; Harman, 2011; Harman, 2016; Nkangu, Olatunde, and Yaya, 2017; Smith, 2019).

#### *Physiological dimensions of disease and the increased risk of transmission*

It is well understood that a women's physiology means she is more vulnerable to some communicable diseases, particularly those which are transmitted through (consensual and non-consensual) sexual intercourse such as Zika and HIV/AIDS (Anderson and Beresford, 2016; Batchtold, 2020; Diniz, 2017; Diniz, Ali, Ambrogi and Brito, 2020; Harman, 2011, Smith, 2019). The biological implications of disease impact women severely, demonstrable in the disproportionate infection, morbidity and mortality rates compared to men (Harman, 2011). This is particularly evident in HIV/AIDS which Harman (2011) describes as being "increasingly (...) identified as a feminised epidemic by the national governments, international organisations, donors, and non-governmental organisations that have come to constitute the global response to the problem" (p. 214). She claims this is primarily due to the disproportionate number of women being infected and affected by HIV/AIDS compared to men. A disparity which she claims is widely attributed to women's biological vulnerability. Specifically, "the physiology of male and female sexual intercourse; and the increased inflammation of mucosal surfaces through cross-infection with other sexually transmitted infections (STIs) and possible trauma" (Harman, 2011, p. 214).

Similarly, studies of the 2015-16 Zika outbreak in Brazil reveal it to be a highly feminised epidemic, attributable to both the physiological and social impacts of the disease on marginalised and affected women. Diniz (2017) and Batchtold (2020) explain that women were at an increased risk of contracting Zika due to physiological vulnerability to the sexual transmission of the virus (being one mode of transmission) which was not well understood at the time. In their socially constructed roles of homemaker and caregiver, Brazilian women affected by the Zika outbreak were burdened with controlling the Zika carrying mosquito (Batchtold, 2020; Diniz, 2017; Diniz et al., 2020). This burden significantly increased their risk of transmission through increasing their proximity to the mosquito. Similarly, Harman (2011) found women in India were also disproportionately infected and affected due to gender inequalities and their place in society and the family. She describes how a "high percentage of women were infected with HIV by their husbands" due to their lack of sexual autonomy and lack of property rights which reduced their "ability to leave abusive relationships" (Harman, 2011, p. 215). While in Sierra Leone the burden of caring for Ebola patients fell to women due to an insufficient health system which had "direct implications for their risk of contracting" the virus (Anderson and Beresford, 2016, p. 477). Similarly, an Ebola outbreak in the DRC during 1976 saw women's risk of transmission significantly increase

as they took “on the role of ‘nurses’ in their homes” to care for the sick (Nkangu, Olatunde and Yaya, 2017, p. 6).

#### *Cultural expectations around care and an increased risk of transmission*

Cultural expectations around caregiving can greatly exacerbate a woman's risk of transmission. Referring to Ebola, Nkangu et al. (2017) describe how gendered roles put people at an increased risk of transmission both indirectly and directly. Indirectly through “sharing meals, washing clothes, sleeping in the same bed, sharing clothing, shaking hands, or hugging, as well as during ritual hand washing and communal meals at funerals” and directly through “contact with infected patients, dead bodies, or bodily fluids” (Nkangu et al., 2017, p. 4). Cultural expectations around caregiving and domestic tasks means women are at a significantly higher risk of contracting Ebola. Moreover, this is often exacerbated intentionally, for example, Congolese and Gabon “men deliberately made use of the social custom that women care for the sick in order to avoid contact with [Ebola] patients” (Fawole et al., 2016, p. 3). The risk of infection was not limited to caring for the living or performing domestic tasks, it also includes caring for the dead. Davies and Bennett (2016) explain that “women’s traditional roles as carers (both within the family and as health-care workers), and as the people who traditionally prepare bodies for burial, placed them at particular risk of exposure to Ebola” (p. 1047). Women who performed their gendered role of caregiver in accordance with cultural expectations were at increased risk of contracting Ebola. This risk was greatly exacerbated by a lack of personal protection equipment (PPE).

#### *The inequalities of risk for women in the care economy*

A woman's risk of transmission whilst performing her care role is significantly increased when there is no access to adequate PPE. In so, highlighting inequalities in the way care is performed. Pallister-Wilkins (2016) claims that “not everyone [working with Ebola patients] was the subject of protection” and “in certain instances already existing structural and racial hierarchies between international humanitarian workers and local health workers treating Ebola were reproduced” (p. 516). Demonstrable in the lack of PPE which highlights the inequality between local and international humanitarian health workers, the adverse implications of which are profoundly felt by women. The disparity in outcomes between healthcare workers in the formal care economy was also acutely felt when international caregivers who contracted Ebola treating patients in Monrovia, were “evacuated back to North America and Europe for treatment in state-of-the-art infectious disease units” while some “500 local medical workers lost their lives, starkly highlighting the structural differences in public health provision” (p. 516). The disparity of inequality was also felt by informal caregivers when MSF (Médecins Sans Frontières) knowingly handed out some 600,000 woefully inadequate ‘home disinfectant kits’ (...) in order to reduce infection risk” (p. 516).

The lack of PPE in health is an ongoing problem and one which impacts women who are at the forefront of caring for disease affected family members, communities and often the dead as well. Smith (2019) argues that irrespective of the many health-based programmes run by NGOs and state health sectors much of the care work is still “reliant on the unpaid care work of women, [who] are usually poorly resourced, and are ill-equipped to deal with outbreaks” (p. 363). Harman (2011; 2016), Smith (2019) and others, have illustrated that there is a direct correlation between a woman's socially and culturally constructed role of caregiver and her increased risk of transmission. Yet, policies and interventions which seek to instrumentalise the gendered role of caregiver are doing so in the knowledge that they are placing women at significantly increased risk of transmission. For example, Harman (2011) argues that while the World Bank (WB) recognises the disparity in infection vulnerability of women this does not translate into “policy, with women being rolled into the social aspect of HIV/AIDS as an ‘issue’ as opposed to addressing the feminisation of the epidemic” being both physiological and social inequalities (p. 222). The gender role of caregiver has also been instrumentalised in health governance as a way to address gender inequalities through including women and gender.

#### 3.4.3 Women and governance: Just add women

One of the ways global health deals with disease is through including or adding women to local and global governance structures. Yet, as Harman (2016) suggests, this is often a powerless, token gesture with no notable outcomes for women or gender equality because it disregards the structural inequalities which drive gender inequality (p. 224). This is particularly evident within the context of HIV/AIDS and East Africa where she claims that “international organisations, government agencies, and nongovernmental organisations [included women] as a key mechanism to address the feminisation of the epidemic” (p. 224). Adding women to governance structures is promoted by UNAIDS who stipulate that “women must be adequately represented in policy and decision-making on HIV/AIDS (UNAIDS as cited in Harman, 2016, p. 216). The assumption that adding women will fix the problem of disease is perhaps most notable in community-based and national governance structures. Supported in part, by the emphasis placed on this approach by “international organisations such as UNAIDS and the World Bank [who have] (...) broadened the scope and space in which women operate” (Harman, 2016, p. 216). For example, in “Kenya, Tanzania, and Uganda, women occupied senior positions of authority within the national HIV/AIDS councils (...) [focusing on] community organisation and district support” (Harman, 2016, p. 216). Adding women to global level governance has seen them take up positions on “boards and committees of international coordinating agencies such as UNAIDS and the Global Fund” (Harman, 2011, p. 217). The inclusion of women on global governance bodies recognises the contribution that women make in “combating the [HIV/AIDS] epidemic, the importance of presence, and the

importance of women's agency within structures and processes of global decision-making" (Harman, 2011, p. 214). While some women are added to global level governance as a way to address gender inequality, adding women to community-based governance is the most salient way women are added to governance.

The emphasis on community-led governance was a recognition that HIV/AIDS was "driven by socioeconomic and rights-based factors that need to be addressed as well as the health aspects of the disease" and the rise of a multi-sectoral approach which sort to include multiple actors in the response, including women (Harman, 2011, p. 218). According to Harman (2011), adding or 'including' women to HIV/AIDS governance bodies was seen to have several benefits, namely, it demonstrated that gender concerns were being acknowledged and addressed, including gender perspectives which promoted "gender sensitivity through practice" (p. 218). Within the context of sub-Saharan Africa, she claims women's groups had already mobilised themselves within their communities and were providing "care and education", these groups were "formalised into loosely structured organisations" and added to the response through targeted funding (p. 218). They were "encouraged to work with local authorities in formulating the district and community HIV/AIDS strategic plans" and "coordinate the activities of other community groups and CSO [civil society organisations] activity in the area" (p. 217). This saw a "transition of women's participation from implementation to direct influence upon local decision-making and agenda-setting" (p. 217). Hence, the focus on community initiatives as the primary response vehicle has "indirectly positioned women as the main focus of global HIV/AIDS governance" and squarely placed the success and failure of community-based initiatives on women's shoulders (p. 218). While a few women's groups have successfully navigated the governance inclusion space, overall, this approach has not resulted in better outcomes for women (Harman, 2011).

Harman, (2011) attributes this to two factors, first, the type of inclusion, and second the rationale that the inclusion of women leads to better outcomes for women (p. 224). The latter leads to one of the more salient takeaways from Harman's argument about the ways in which women are dealt with in contemporary health. Namely, the mere presence of women in governance bodies does not guarantee gender equality. Adding women as a way to deal with gender inequality issues wrongly assumes that "all women are the same and that all women will engage in issues of gender politics" (Harman, 2011, p. 223). Moreover, whilst

women were aware of various approaches to gender (...) they did not necessarily prioritise the issue over others, or if they did there was nothing to suggest this was because they were active feminists (with the exception in some cases of those working within gender-specific units or programmes) or because they were women (Harman, 2011, p. 223).

The notion that adding women to governance structures will address the problems of gender inequality has been a misstep in global health governance. Not only does it devalue women through only valuing their role as caregivers, it homogenises women and gender through wrongly assuming that all women are the same.

### 3.5 Why adding women and gender failed to deal with gender inequality

As illustrated by Harman, simply adding women to the problem of disease has not resulted in better outcomes for women and gender and it has often resulted in the exacerbation of gender inequality. In her analysis of HIV/AIDS Harman (2011) offers three key reasons which explain why this approach failed, “the problem of gender mainstreaming, the politics of presence, and the side-lining of gender expertise” (p. 219). While this explanation relates to HIV/AIDS, I suggest it could also explain gender inequality issues present in Ebola and Zika governance.

#### 3.5.1 Gender mainstreaming

Theoretically, gender mainstreaming posits that “integrating gender considerations into policies and programmes would rectify the power imbalance between men and women and, in the health sector, result in improved health outcomes” (Gupta et al., 2019, p. 2553). This often takes the form of including or adding women to governance structures to address gender imbalances under the guise of ‘gender mainstreaming’. While gender mainstreaming can elicit better outcomes for marginalised women it can also be ineffective and cause harm when it is ill-conceived, guided by competing interests, becomes a box-ticking exercise and lacks political will. Harman (2011) illustrates “the problem of gender mainstreaming” in the context of HIV/AIDS, identifying key issues which render it ineffective and harmful to women (p. 219). Namely, the relationship between gender mainstreaming and donor funding requirements, the lack of conceptualisation and poor use of gender mainstreaming by governments and organisations and the lack of political will to address gender inequalities and acknowledge health problems (p. 220).

The toxic relationship between gender mainstreaming and donor funding agendas is exemplified in the context of HIV/AIDS and East Africa. In order for the governments of Uganda, Kenya and Tanzania to secure funding for their National Strategic HIV/AIDS Plans they had to align their intervention programmes with donor agendas and “own those agendas as their own” (Harman, 2011, p. 220). Harman (2011) asserts this confined gender mainstreaming to little more than a meaningless box ticking exercise to secure donor funding, in so reflecting a broad trend in which gender mainstreaming is utilised by “international organisations and states with little recognition of its purpose or outcome” or how it will function within the “context of a country’s specific epidemic” (pp. 220-225). The failure of governments and organisations to properly conceptualise and use gender mainstreaming results in woefully inadequate measures, which equate to no more than “equal inclusion of men



and women in delivery of services, discussion forums, and the funding of a number of women's organisations at the national and community level" (p. 225). Moreover, she argues that there is a general lack of "awareness of women and gender at the state level" and when gender mainstreaming is used, it only values women in terms of their SRH roles, namely their care role in their community (p. 220). While there is some evidence of meaningful gender mainstreaming in Tanzania due to clearly defined objectives which outline how to deal with the feminisation of HIV/AIDS, overall, gender mainstreaming in Uganda, Kenya and Tanzania was poorly articulated and meaningless (Harman, 2011).

### 3.5.2 The politics of presence

Harman's (2011) analysis of HIV/AIDS governance in East Africa also showed that like gender mainstreaming, the "politics of presence and how women are included" is also problematic (p. 221). As previously illustrated, the inclusion of women in health governance is often tokenistic and powerless and used to fulfil donor requirements around gender mainstreaming. She explains that the fundamental expression of the politics of presence is the "male domination of HIV/AIDS governance bodies and the marginalisation of women" (p. 222). It also sees "men dominate proceedings, and their thoughts and opinions (...) prioritised over those of their female counterparts" (p. 222). In one example she explains that while women held positions as community coordinators and facilitators within the National Aids Control Council (NACC) HIV/AIDS governance structures, "roles in finance, procurement, strategic planning, and donor coordination were filled by men" (p. 217). Consequently, women are typically confined to roles of care, primary education, and implementation. This marginalisation of women means they are "only able to gain leverage in decision making by reasserting their caring function and close links with the community" (p. 222). Harman (2011) argues that confining women's inclusion to care roles aligns with "the interests of those actors at multiple levels of governance" who understand that women fill gaps in weak health systems (p. 222). Hence, the relationship between women and HIV/AIDS governance becomes explicitly coupled to their gendered role of caregiver and as previously illustrated, gender and women are conspicuously invisible in this role. Both Harman (2016) and Smith (2019) attribute the conspicuous invisibility of women and gender to gender blindness and Elson's (1995) argument that an unconscious male bias exists within global health. Moreover, as I will come to show, male bias underpins the side-lining of gender expertise within health organisations.

#### *Gender blindness and male bias*

Gender blindness and male bias harms women, whether it is intentional or unintentional the outcomes are the same. Women are effectively silenced across all levels of health, from the local to the global. They remain conspicuously invisible except for a few who are afforded a voice, albeit one that is only valued in relation to

her SRH. According to Elson (1995, as cited in Harman, 2016), male bias in global health renders women invisible because it is blind to the economic structures which favour men over women. Moreover, when health systems are gender blind it can exacerbate and reinforce gender inequality in terms of daily functions and policy (Payne, 2009). Harman (2011) argues that male bias is problematic because it limits any “structural thinking about women and/or gender” thereby, reducing women and gender to a “single development issue, to be engaged with in specific projects when they are affecting successful project outcomes in the ‘other’ of developing countries” (p. 224). Or put another way, male bias means women and gender are foremostly seen and dealt with through a development lens and not a health one. This is exemplified in the recasting of HIV/AIDS from a health issue, to a development issue, which saw male bias shape “development outcomes that were preferential to men” and their needs (p. 224). Harman (2011) argues that dealing with male bias in health and development cannot be adequately addressed simply through adding women to the problem and adopting gender mainstreaming policies. Similarly, Smith (2019) raises the issue of gender blindness and male bias at the global governance level warning that the “uncritical promotion of security-sector engagement in disease outbreak responses reinforces a specific type of masculine dominance in decision-making and may exacerbate insecurity for women and marginalised groups” (p. 359). Furthermore, when gender blindness and male bias control how women are added to governance structures and the problem of disease, it silences women’s voices through controlling the story. When men dominate the story of disease

it increases the space men take up in our narratives and imagination on global health, reproducing the norm of men as leaders and individual visionaries that get things done—the single heroic leader with the necessary vision, dynamism, and obstinacy to address the world’s greatest problems (Harman, 2020, p. 777).

Male bias is reinforced through their dominance and control over stories of disease. For example, Harman (2020) describes how “men working in global health have cemented their leadership through biographies and high-profile interviews that focus on their life stories” such stories have contributed to rendering women conspicuously invisible (p. 777). In reference to HIV/AIDS and local governance, she argues that men dominated “proceedings, and their thoughts and opinions were often prioritised over those of their female counterparts” (p. 222). Women who were present during such community proceedings were “pigeonholed into positions of implementation, care, and primary education”; their voices were only heard and/or valued in decision making when they spoke from their gendered role as caregivers within their community (p, 222). As previously illustrated, keeping women confined to their gendered roles as caregivers aligns with a wide-spread global health agenda which relies on the unpaid labour of women to strengthen weak health systems

(Anderson and Beresford, 2016; Harman, 2011; Leach and Dry, 2010; McInnes, 2016). Furthermore, when gender blindness and male bias persist, women and their voices are ignored; “too often when we dismiss stories, we dismiss women” (Harman, 2020, p. 776).

Harman (2020) warns that when women’s stories are dismissed, we miss the opportunity to learn from their “everyday knowledge (...) [and experience] of how health systems function in particular settings”, often gathered at the coal face of disease (p. 776). Women’s stories are also dismissed because they disrupt and confront male dominated health system governance, policies, and agendas (Harman, 2020). In particular, she claims these kinds of stories are problematic for those in health as they may “contradict scientific evidence” drawing on other kinds of knowledge including personal experience (p. 776). She warns that dismissing the stories of women dismisses the reality of their lived experiences and will not lead to change. Finally, as previously stated, gender blindness and male bias is deeply entrenched and widespread in health and development, from the local to the global, affecting policy and programmes, and impacting women in often harmful ways. While male bias permeates global health, Harman (2016) suggests gender blindness may not be intentional, offering an explanation in the ‘tyranny of the urgent’.

#### *The tyranny of the urgent*

Harman (2016) asserts,

there is an argument that suggests the failure to recognise women and issues of gender in the Ebola response was not wilful blindness but born out of the emergency situation those combating the epidemic found themselves in (p. 534).

According to Davies and Bennett (2016), the ‘tyranny of the urgent’ deals with the immediate concerns of a health crisis and “puts aside for ‘later’ the structural issues—in this case, whether women have economic, social or regulatory options to exercise the autonomy presumed in the international advice” (p. 1044). Problematically, dealing with Ebola and Zika in such ways ignores the structural drivers behind the crisis, thereby exacerbating gender inequality. For example, Davies and Bennett (2016) describe how responses at the outset of the Zika outbreak, such as “women asserting reproductive autonomy” were subverted in the rush to respond (p. 1044). Although the ‘tyranny of the urgent’ may account for some unintentional gender blindness it does not explain the persistent and entrenched gender blindness in global health which also manifests in the side-lining of gender expertise.

### 3.5.3 Side-lining expertise

The response to HIV/AIDS has at times seen the side-lining of gender expertise (Harman, 2011). The most salient example of this relates to the exclusion of UN Women from UNAIDS, in so, revealing a side-lining of gender expertise in several ways (Harman, 2011). Harman (2011) argues that the exclusion of UN Women suggests that they did “not represent an issue of importance to UNAIDS” and lacked the ability to be a co-sponsor on their own merit, despite their gender and women focused role at the UN. UN Women were instead represented by the “Gender Programme Team, within the Social and Economic Development Group” of the United Nations Development Fund (UNDP) (Harman, 2011). Further, she asserts that those within UNAIDS who represent “issues of women and gender are not necessarily feminists or experts on women and gender, specifically the politics of mainstreaming and inclusion” (p. 223). Importantly, being a co-sponsor “confers a degree of legitimacy” therefore, side-lining UN Women and their gendered expertise confers a lack of legitimacy (p. 223). Harman (2011) warns that the exclusion of UN Women excludes “critical engagement with the concepts of women and gender and how they pertain to the global HIV/AIDS response” (p. 223). While it is deeply concerning that UN Women are side-lined from an active role in UNAIDS other co-sponsors such as the World Bank (WB) speak to gender issues through their own embedded gender units (Harman, 2011). Yet, as Harman (2011) points out these are ineffective because they fail to consider the “structural determinants of the feminisation of HIV/AIDS, i.e., those socio-economic factors that make women economically dependent on men, situate women and girls in a primary care role, and limit female access too choice” (p. 223). Moreover, they are ineffective because they deal with gender and women as a “single development issues to be engaged with in specific projects” reflecting a shift in focus from health to development (p. 224). Finally, Harman argues that the side-lining of gender expertise reflects a “wider trend of male bias within the development policy process” which prioritises the needs of men over women (p. 223).

### 3.6 Conclusion

Critiques of global health’s treatment of women and gender reveals an approach to disease which fails to adequately consider the gendered dimensions of disease. This is demonstrable in the presence of gender gaps in global health policy and the lack of action from powerful global health actors who are mandated with addressing health and gender inequality. When gender and women are considered, they are dealt with through narrow and harmful responses which explicitly target their SRH while failing to consider the broader gendered dimensions of health and disease. While an SRH approach is needed, it is injurious to women when it becomes the primary focus and women’s care burdens are exacerbated. In chapter seven, my analysis shows that women are often reduced to reproductive, biological bodies to be dealt with through targeted SRH interventions

while structural inequalities are overlooked. It also shows that a woman's gendered reproductive role is fundamentally seen as a resource in global health, demonstrable across Ebola, Zika and HIV/AIDS and the ways in which women and their SRH roles were instrumentalised in the prevention, management, and containment of these diseases, particularly in the role of caregiver.

The paradox in global health governance has seen women rendered conspicuously invisible, except for a rare few who occupy positions within global health governance such as the current executive Director of UNAIDS, Winnie Baniminya (UNAIDS, n.d). For most women, their lived experience of disease is visibly invisible. While they are seen and acknowledged for their tremendous work in the care economy, Harman (2011) argues that this does not translate into gender sensitive policies and programmes. The ways in which women and gender are treated in contemporary health governance exacerbates gender inequality and stigmas as I will come to show through exponentially increasing their workloads and reinforcing harmful gendered assumptions about the role of women. Moreover, women continue to be constructed as helpless victims in need of interventions. Problematically, this often means that the structural drivers of inequality are overlooked in favour of emancipating women from abusive men and relationships. Harman (2016) warns that failing to make women and gender visible reinforces weak health systems and their reliance on women to fill gaps in the care economy. Moreover, it harms women through reinforcing "gender assumptions and the conspicuous invisibility of women in care" (p. 525). My analysis in chapter seven shows that women's gendered roles as caregivers were exploited by global health actors in both the formal and informal care economy, in the prevention and management of Ebola, Zika and HIV/AIDS. It also shows that women were conspicuously invisible across all three epidemics.

## CHAPTER FOUR: METHODOLOGY

### 4.0 Introduction

This chapter outlines the methodology used in this research. It also seeks to highlight the robustness and value of doing desk-based policy research, particularly in the current COVID-19 context where generating primary data through fieldwork has for many researchers become, for the time, untenable. Finally, I consider my own positionality.

### 4.1 Methods

This research uses qualitative research methods to answer the research questions. Braun and Clarke (2019) describe qualitative research as being concerned with “meaning and meaning-making, and viewing these as always context-bound, positioned and situated,” they also suggest it is about “telling stories” and “interpreting, and creating, not discovering and finding the ‘truth’ that is either ‘out there’ and findable from, or buried deep within, the data” (p. 591). Fundamental to this approach is flexibility and the role of the researcher whom they position as an active participant generating themes from the data.

### 4.2 Critical discourse analysis

This research uses critical discourse analysis (CDA) following Faille (2011) and Ziai (2015) who assert discourse analysis has been successfully used to interrogate discourses of underdevelopment, specifically around relations of power. Faille (2015) suggests critical discourse analysts working in international development studies (IDS) share Fairclough and Wodak (1997), and Van Dijk’s (1997) concern with speech, text and imagery, being “elements of social practice and tools used to communicate values and meanings” (p. 224). Faille (2011) argues that speech, text and imagery are employed as “strategies to reinforce the legitimacy of one group” whilst marginalising others (p. 224). Moreover, he claims that discourse analysts working in IDS have “successfully studied and criticized gender, cultural and class discrimination in speech, text and images at almost all levels of social cohabitation, harmonious or not” (p. 215). Similarly, Ziai (2015) suggests that discourse analysis has contributed to exposing the “relations of power implicit in the discourse” moreover, it has contributed to illuminating issues of “naturalization, othering, legitimization, hierarchization, depoliticization and appropriation” (p. 17).

#### 4.2.1 Discourse analysis and international development studies

Discourse analysis emerged in international development studies (IDS) during the 1990’s and is frequently attributed to the work of Arturo Escobar, James C. Scott, James Ferguson, Gilbert Rist along with some working in gender studies such as Chandra Mohanty (Faille, 2011; Ziai, 2015). However, it must be

acknowledged that there were earlier critiques within development studies around the “idea of development” in terms of discourse, prior to Foucault’s popular concept of *discourse* (Ziai, 2015, p. 1).

The use of discourse analysis in IDS is the cause of debate and tension; Faille (2011) and Ziai (2015) hold differing views on the use and embeddedness of discourse analysis in mainstream development studies. Faille (2001) argues discourse analysis was marginalised in mainstream IDS during the 1990’s while Ziai (2015) challenges this claim and asserts it is deeply embedded in IDS demonstrable in the number of scholarly works using discourse analysis and its “presence in academic debates” (p. 1). One of the reasons Faille (2011) proffers for the marginalisation of discourse analysis in IDS during the 1990s is the lack of IDS scholars’ association with established schools of discourse such as CDA, of which he is quite critical calling it a “serious shortcoming” (p. 223). However, Faille (2011) does acknowledge that the aforementioned discourse analysts (and many others in IDS) are united in their “rejection of mainstream analysis of underdevelopment” and view the “study of speech, text and image as new paths toward understanding the causes of underdevelopment” (Faille, 2011, p. 215). Moreover, he suggests they view speech, text and imagery as “elements of social practice and tools used to communicate values and meanings”, in so, following the traditions of CDA founders Fairclough (1993), Fairclough and Wodak (1997) and Van Dijk (1997) (p. 223). Fairclough and Wodak (1997) regard “language as a social practice” in so, aligning with Foucault’s assertion that *discourse* is the “systematically construct(ed) version of the social world” (p. 570).

Faille (2011) claims that “discourse analysts have successfully studied and criticized gender, cultural or class discrimination in speech, text and images at almost all levels of social cohabitation, harmonious or not” and when applied to *underdevelopment* discourse reveals that problems associated with *underdevelopment* might “reside in ideas, categories and strategies as they materialize in speech, text and images” thus revealing the power dynamics and ideologies at play (pp. 215-222). Similarly, Ziai (2015) claims that discourse analysis has “yielded crucial insights for development studies” in the areas of, naturalization, othering, legitimization, hierarchization, depoliticization and appropriation (p. 7-8). Irrespective of their differing views, both Faille (2011) and Ziai (2015) agree that the focus on speech, text and imagery has been successfully utilised by various scholars working in IDS to advance the understanding of ‘underdevelopment discourse’. Finally, Faille (2011) suggests that discourse analysts working in IDS have demonstrated the important role framing plays in revealing problems and issues, and that these “may in fact lie in the very framing or representation of the identified issues [and problems]” under analysis (p. 232). Framing in this sense has shown that the ways in which problems and issues are framed is often due to “biased (...) notions that are culturally insensitive” and

“these notions carry insidious preferences for class or gender” (pp. 232-233). Given Faille (2011) and Ziai’s (2015) arguments around discourse analysis’s use in IDS it is pertinent to be clear about the discourse analysis school this study is aligned with being CDA. More clearly aligning with a school of discourse analysis deals with some of the criticisms levelled at discourse analysis and CDA, including those of Faille (2011), Ziai (2015), as well as Fairclough (1992), Schegloff (1998) and Widdowson (1995).

According to Meyer (2001), “it is generally agreed that CDA must not be understood as a single method but rather as an approach” (p. 2). Moreover, it is widely acknowledged that CDA, in its various approaches, is foremostly concerned with uncovering relationships of power (Faille, 2011; Fairclough, 1997; Fairclough and Wodak, 1997; Wodak, 2001; Ziai, 2015). Specifically, CDA is interested in the relationship between language and power (Wodak, 2001). CDA is also interested in issues of responsibility and ideology (Wodak, 2001). To that end, it is the *critical* aspect of CDA which exposes the often-hidden aspects of language, power and ideology (Fairclough, 1989). Although CDA is predominantly applied to media analysis, it has also been applied to other institutional and organisational actors where power, ideology and discourse intersect such as the WHO. In terms of media, it has been used to show “how certain social groups may be ill-represented or misrepresented in various types of discourse” and it has revealed “the importance of language used in media in generating the taken-for-granted claims about women and the media’s reinforcement on hegemonic ideologies of gender” (Sriwimon and Zilli, 2017, p. 137). Similarly, Carant (2017) asserts that CDA can reveal “preferred solution frames that tend to reinforce existing institutional relationships” (p.17). Moreover, unlike other analytical approaches CDA actively seeks to move beyond discretion and analysis to bring about change through exposing power (Faille, 2011; Fairclough and Wodak, 1997). Faille (2011) argues CDA “must contribute to building alternative practices for increased autonomy in decision making, [and] more inclusive social fabrics and global respect of cultural differences” (p. 234). CDA can therefore be understood as a form of social action (Fairclough and Wodak, 1997).

#### 4.2.2 Criticisms of CDA

Ziai (2015) lists four key criticisms levelled at discourse analysis in IDS, including, the predominant “focus on discourse risks losing sight of materiality” thereby neglecting “material questions of poverty and survival in capitalism”; second, when applied to IDS, CDA runs the risk of “homogeniz(ing) different, even opposing discourses into a single monolithic entity”; third, “Foucauldian approaches to discourse analysis construct a pervasive and all-powerful discourse, thereby losing track of questions of agency” and finally, “the critique of discourse is unable to provide political alternatives” (p. 2). Faille (2011) suggests that “discourse analysts in



IDS have a limited grasp of the general literature on discourse analysis” both methodologically and theoretically (p. 233). Moreover, he critiques IDS’s typical analysis of perspectives and power as they manifest in higher international development echelons while overlooking the discourse and perspectives which emerge at the bottom. He argues that for discourse analysis to be a “complete perspective” analysis of both the top-down and bottom-up approaches including South-South cooperation initiatives need to be included. Discourse analysis must contribute to building alternative practices for increased autonomy in decision making, more inclusive social fabrics and global respect of cultural differences (Faille, 2011, p. 234).

Fairclough (1992) acknowledges that “discourse is a difficult concept, largely because there are so many conflicting and overlapping definitions formulated from various theoretical and disciplinary standpoints” (p. 3). Widdowson (1995) picks up Fairclough’s assertion and argues that CDA is “extremely fashionable and at the same time extremely uncertain: widespread but spread very thin” and “discourse is something everybody is talking about but without knowing with any certainty just what it is: in vogue and vague” (p. 158). Moreover, Widdowson (1995) and Schegloff (1998) suggest that CDA is not *analysis* per se, but rather an ideological interpretation. Sriwimon and Zilli (2017) suggest that the predominant criticisms of CDA posit that texts are “arbitrarily selected”, “limited in length” and there are “limitations and difficulties in drawing any conclusion” (p. 137). In order to address the criticisms around data collection this study follows Sriwimon and Zilli’s (2017) position that these can be overcome through utilising “a rigid and well-structured CDA” following Reisigl and Wodak’s (2009) criteria which sets specific boundaries around data collection (pp. 136-137).

#### 4.3 Literature review: Insights into the relationship between women, gender and health

Before commencing secondary data collection and analysis, I undertook a literature review to gain insights into the relationship between epidemics and gender. I engaged with a broad range of literature around Ebola, Zika and HIV/AIDS which established the argument that epidemics are not gender neutral; women and men experience epidemics in different and disproportionate ways and this can be exacerbated through a lack of gender perspective in global health policy (Harman, 2011; Harman, 2016; Smith, 2019). The literature review both confirmed some of the pre-existing assumptions I had about how WHO and CARE policy might deal with gender issues in relation to epidemics and generated some new assumptions around gender and epidemic policy. It also revealed that the relationship between gender, health policy and epidemics are understood in different ways depending on disciplinary tradition.

## 4.4 Secondary data

### *Note on the use of the term documents*

Documents in this study refer to dated, English language, publications, reports, news releases, statements, stories and educational material published on the websites of the WHO and CARE. Undated material was not included in this research to ensure robustness and rigor.

#### 4.4.1 Why I chose the WHO and CARE

As the premier global health organisation mandated with providing advice to countries on the prevention, management and containment of epidemics I elected to focus on the WHO as one of two global organisations to answer my research question. The WHO is deeply involved in policy and programmes across all three epidemics I elected to focus my research on. CARE is an international humanitarian INGO focused on addressing gender inequality and social injustices for women and girls.

This study was initially also going to use data from English language mainstream media and UN Women. However, after careful consideration, I elected to focus on the WHO and CARE due to time constraints around the collection and analysis of secondary data.

#### 4.4.2 Secondary data collection and management

This study used secondary data which was collected following Reisigl and Wodak's (2009) systematic data criteria approach which sets specific boundaries around data collection to ensure robustness and rigor in both data collection and analysis (p. 98). I chose this approach because it seeks to address criticisms levelled at CDA in terms of researcher bias in selecting texts and a lack of rigor which "leads to concerns over the credibility and trustworthiness of the research" (Sriwimon and Zilli, 2017, p. 137).

In accordance with Reisigl and Wodak's (2009) approach, a tentative date-range was identified as the decade 2008-2018. Working to this date-range, I undertook online scanning across Google Scholar, WHO, CARE and UN Women websites using keywords such as 'Ebola', 'Zika', 'HIV/AIDS', 'women', 'woman', and 'gender' to identify relevant documents to answer my research questions. However, it soon became apparent that working within the date-range 2008-2018 was challenging as each epidemic had its own specific date-range with HIV having a much longer range to consider. To accommodate this, I adjusted my date-range to align as best I could with the epidemic events under investigation and to allow for enough data to be generated. I settled on the date-range 2010-2018.

Once the relevant documents were located within the date-range they were imported into NVivo files. After considering a paper-based management system I decided that NVivo was better suited to organise the large and varied digital data set. This decision was also influenced by the COVID-19 restrictions at the time which

prohibited travel, meaning the University of Auckland and other printing services were inaccessible. I also considered Dropbox, but I felt the data set was too large and varied to organise in an easily retrievable way. NVivo enabled the data to be easily organised and accessed. I discuss coding in section 4.5.2.

#### 4.4.3 Benefits and limitations of working with secondary data

Bryman (2016) suggests that while there are benefits in using secondary data such as, cost and time associated with data collection and analysis, high quality data and the benefits of reanalysing data which may provide new interpretations there are also limitations (pp. 310-312). He suggests limitations include a “lack of familiarity with data” which takes time to establish, also the complexity of the data may require more time to become familiar with the data, also the lack of “control over data quality” and the “absence of key variables” (pp. 312-313). I experienced some limitations working with secondary data, namely, a lack of familiarity with the data, particularly in reference to the WHO whose policy is typically complex, scientifically and medically technical, dense and targeted primarily towards the public health arena, an area I have limited experience in. Additionally, many of the WHO policy documents were lengthy and live (being continually updated), as such finding dated documents within my specified date range was challenging. Overall, I found that the time constraints of a master’s thesis within the context and challenges of the COVID-19 pandemic meant the benefits of cost and specifically time were advantageous. It also meant that I could pivot my initial research towards policy-based research using high quality data. My experience of undertaking research using secondary data greatly outweighed the limitations. Moreover, the ability to utilise secondary data meant I was able to quickly pivot my research and continue in a timely manner with a degree of certainty that COVID-19 restrictions would not further impede my research. I reached data saturation quickly as both the WHO and CARE employ a narrow and prescriptive set of policies.

#### 4.5 Thematic analysis

Braun and Clarke (2017) describe thematic analysis (TA) as a “method for identifying, analyzing, and interpreting patterns of meaning (‘themes’) within qualitative data” (p. 297). TA offers a “toolkit for researchers who want to do robust and even sophisticated analyses of qualitative data” (Braun and Clarke, 2014, p. 2). The value of a TA approach, they suggest, lies in its ability to analyse “data in many disciplines and fields” and its wide application across varied datasets, including health, and “different research questions” (Braun and Clarke, 2014, p. 2). Thematic analysis can also be used “within a ‘critical’ framework, to interrogate patterns within personal or social meaning around a topic, and to ask questions about the implications of these” (Braun and Clarke, 2017, p. 297).

#### 4.5.1 Reflective thematic analysis (RTA)

Reflective thematic analysis (RTA) is an approach to TA developed by Braun and Clarke (2019) beginning with their initial TA first posit in 2006. They describe their version of TA as providing a “robust, systematic framework for coding qualitative data, and for then using that coding to identify patterns across the dataset in relation to the research question” (2014, pp. 1-2). Key components of their approach include the central role of the researcher whom they describe as bringing *sophistication* to the research through actively participating in generating and interpreting themes (2019). Flexibility is another key aspect Braun and Clarke (2019) suggest offers the “qualitative researcher flexibility in terms of the theory informing their use of TA, and how precisely they enacted” it (p. 592). They are careful to point out that flexibility requires the “researcher to articulate the assumptions that informed their approach and how exactly they enacted TA” (p. 592). Braun and Clarke (2019) treat themes as “stories about particular patterns of shared meaning across the dataset” brought out of the data through the active engagement of the researcher (p. 592). Finally, RTA follows a six-phase, recursive methodology, including actively engaging with the data, and generating codes and themes (Braun and Clarke, 2006; 2016; 2017; 2019). This research attempts to apply this approach to answer the research questions.

#### 4.5.2 Data coding

Braun and Clarke (2019) claim their RTA approach can use all variations of TA, including variations in data coding. They argue that ‘rigid separation’ of data coding approaches is not guaranteed and some may overlap and blend together. This research uses both inductive and deductive coding approaches. Inductive coding and theme development are directed by the content of the data while deductive coding is directed by existing concepts or ideas (Braun and Clarke, 2006; 2014; 2019).

Data coding began with data familiarisation. Braun and Clarke (2006) recommended researchers become immersed in the data. By this they mean, a process of repeated and active reading of the data searching for meanings and patterns. This process begins with a cursory reading of the entire data set at least once before beginning the coding process as this initial reading may reveal “ideas and [facilitate the] identification of possible patterns” (p. 87). With that in mind, I read and re-read, familiarising myself with the data. This was a daunting process due to the complexity and length of the data, specifically WHO data. I began noting down tentative deductive and inductive codes. Inductive codes were generated from the data and predominantly yielded interesting themes organised around central organising ideas and insights, specifically around gender in relation to health policy and epidemics. Deductive codes were informed by existing ideas and concepts around epidemics as articulated by Wald (2008) specifically ‘the outbreak narrative’ and Leach and Dry’s (2010) dominant and alternative narratives. Although Braun and Clarke (2019) do not advocate using a

codebook in their RTA approach, I elected to use a modified codebook in NVivo to organise the codes because it helped provide some structure around the coding process. This was particularly useful in terms of organising deductive codes. The codebook references were then printed out so I could visualise and physically play around with theme generation by moving codes around on a table.

#### 4.5.3 Theme generation

During this phase, I adhered to Braun and Clarke's (2019) argument that themes do not *emerge* in the data, they are already there and are generated and interpreted through the researcher's active engagement with the data. With this in mind, I looked for themes that clustered around central ideas, avoiding as best I could the development of domain summaries, which are summaries of a topic or data rather than "patterns of shared meaning underpinned by a central organising theme" (Braun and Clarke, 2019, p. 5). Braun and Clarke (2019) define central ideas as the glue that holds the theme together. Once I had an initial set of themes, I reviewed them looking for overlaps, and replication, this resulted in some themes being dropped and others being merged. During this phase I oscillated between the data and analysis whilst being constantly aware of my positionality and active role as researcher. Themes became discussion points in chapters six and seven.

#### 4.5.4 Criticisms of Reflective Thematic Analysis (RTA)

Braun and Clarke (2019) claim that the predominant and most frequent criticism levelled at TA and RTA is a perceived lack of sophistication. Moreover, questions around its "validity (...) as a method, or as a method suitable for (...) [a] particular research project" (Braun and Clarke, 2014, p. 1). A further issue is its inability to "address issues of power and privilege or bring marginalised experiences to the centre" (Lainson, Braun, and Clarke, 2019, p. 96). This is where CDC is particularly useful in highlighting power relations. They also acknowledge that their approach is prone to misinterpretation and confusion resulting in poorly executed RTA. This is not deliberate but done unknowingly, an issue they attribute to a lack of clarity on their part in their initial 2006 paper on RTA (2016).

#### 4.6 Positionality

As a Western cis-gendered woman living in the Global North, my positionality and perspective underpins this research and is informed by my identity, my unique life experiences and my background in development studies and anthropology. Following Harman's (2020) lead, I acknowledge that in conducting and writing this research I am also a storyteller, reproducing and communicating stories about other people. Harman (2020) raises the question of ethics and rightly asks, "who has the right to tell, use, and consume stories?" (p. 777). As such, I am aware that in reproducing stories about women in this thesis, I am also shaping how they are thought about.

## CHAPTER FIVE: INTRODUCING EBOLA, ZIKA AND HIV/AIDS: BIOLOGICALLY AND SOCIALLY COMPLEX DISEASES

### 5.0 Introduction

This chapter provides a descriptive overview of three notable epidemics of the 21<sup>st</sup> Century, Ebola Virus Disease (EVD), Zika Virus (Zika) and Human Immunodeficiency Virus Infection and Acquired Immune Deficiency Syndrome (HIV/AIDS). The purpose is to provide a broad overview of these epidemics as a forerunner to the analysis chapters six and seven which discuss these epidemics in relation to narratives, policy and responses embedded in the World Health Organisation (WHO) and CARE and how this in turn may construct and exacerbate gender inequality through the feminisation of health. Beginning with the WHO's definition of what an epidemic is, it then describes Ebola, Zika and HIV/AIDS in terms of each disease's pathogenesis, clinical presentation, response and the relevant country context of interest to this research.

### 5.1 Epidemics

The WHO (n.d) define an epidemic as,

The occurrence in a community or region of cases of an illness, specific health-related behaviour, or other health-related events clearly in excess of normal expectancy. The community or region and the period in which the cases occur are specified precisely. The number of cases indicating the presence of an epidemic varies according to the agent, size, and type of population exposed, previous experience or lack of exposure to the disease, and time and place of occurrence (p. 11).

Differentially, pandemics are epidemics that affect vast numbers of people across the globe (Kelly, 2011). The 21<sup>st</sup> century has seen a number of "major infectious [epidemic] threats" including, Ebola (West Africa), Cholera (Haiti), MERS-CoV, H1N1, H7N9, Zika, Yellow fever (Central Africa, Brazil), H5N1, SARS, Cholera (Yemen) and Plague (Madagascar) (WHO, 2018, p. 16).

### 5.2 Ebola

#### 5.2.1 Pathogenesis and clinical presentation

According to the WHO (2018) Ebola is understood pathologically to be a "viral haemorrhagic fever that occurs mostly in rural and remote areas of Africa" (p. 56). Transmission occurs via "mucous membranes, breaks in the skin, or parenterally" infecting various cells in the body (Centers for Disease Control (CDC), 2016, p. 1). The CDC and Prevention (2016) describe a number of symptoms in patients presenting with Ebola, these range from "initial nonspecific symptoms" in the first 5-days of infection to severe symptoms and death between 6-16 days. Nonspecific symptoms typically occur include, a rise in body "temperature or subjective fever, chills,

myalgias, and malaise” (p. 1). In some patients these rapidly develop into more specific symptoms including, “severe watery diarrhea, nausea, vomiting, and abdominal pain. Other symptoms such as chest pain, shortness of breath, headache, or confusion also may develop (...) conjunctival injection, seizures and cerebral edema (p. 2). They explain that while “bleeding is not universally present (...) [it] can manifest later in the course as petechiae, ecchymosis/bruising, or oozing from venipuncture sites and mucosal hemorrhage” (p. 1). The CDC (2016) find that patients with more severe symptoms “die typically between days 6 and 16 of complications including multiorgan failure and septic shock” (p. 1). Notably, bleeding is the most familiar and terrifying symptom known to the lay public thanks largely to film and fiction visceral depiction of this symptom and the patient’s subsequent death.

Currently there is a Federal Drug and Administration (FDA) Ebola vaccine rVSV-ZEBOV (Ervebo) (CDC, 2016).

#### 5.2.2 West Africa: 2014-2016 Ebola Outbreak

Within the context of the 2014-2016 outbreak in West Africa, the CDC (2016) reported the most common symptoms as being, “fever (87%), fatigue (76%), vomiting (68%), diarrhea (66%), and loss of appetite (65%)” (p. 1). They also report that patients who succumbed to Ebola complications died a “mean of 7.5 days from symptom onset” (p. 1). One of the challenges in addressing Ebola is the initial vagueness around the nonspecific symptoms which as the CDC (2016) suggest, may cause Ebola to be confused with “other more common infectious diseases such as malaria, typhoid fever, meningococcaemia, and other bacterial infections” (p. 1). This might partially explain the 2-month delay in diagnosing the 2014 outbreak in West Africa (WHO, 2018). Consequently, the WHO reported that this delay “allowed the virus to spread unseen, and to reach capital cities where the outbreaks grew into large epidemics” (p. 18). While this is a very descriptive account of Ebola symptoms it is contextually important to the analysis of Ebola and narratives as it provides for example, some indications as to why this disease may stigmatise affected people via narratives and help explain the logic behind the narrative and the response.

Between 2011-2017 the WHO (2018) recorded some 22 separate epidemic outbreaks of Ebola, 11 of which occurred in West Africa during 2014 (p. 23). Although Ebola was first identified in 1976, the WHO claims that the 2014 outbreak in Guinea, Liberia, and Sierra Leone was “unlike the previous 24 localized outbreaks observed since 1976” (p. 14). What made the West African outbreak different was the geographical spread beyond localized outbreaks; the WHO (2018) reports this outbreak spread to “six other countries in three continents, and [it] sparked alarm worldwide” (p. 15). In such circumstances, it is essential to raise clinicians’

awareness and provide them with the relevant knowledge and diagnostic tools to enable them to perform effectively as detectors and first-line responders (WHO, 2018, p. 18).

## 5.3 Zika

### 5.3.1 Pathogenesis and clinical presentation

Zika outbreaks occur in areas where mosquitos breed and as the Amazon is the largest arbovirus reservoir in the world, mosquito-borne diseases are prevalent (Diniz, 2017, p. 18). The WHO (2018) describes the “current distribution of *Aedes aegypti* is the widest ever recorded (...) [being] present in all continents” (p. 102). The Zika virus was “first isolated in a sentinel rhesus monkey” in 1947 during a study of yellow fever (Diniz, 2017, p. 18). In 1952 it was “isolated from humans” in Uganda and is now recorded in “over 76 countries and territories” notably, for 59 of these, Zika was only detected after 2015 (Diniz, 2017, p. 18).

Zika is transmitted to humans via infected *Aedes* mosquitoes, specifically the *Aedes aegypti* who are known to bite both during the day and at night, indoors and outdoors (WHO, 2018; Maestre, Caplivski and FernandezSesma). Once infected, human to human transmission occurs through sexual intercourse, blood transfusions, organ transplants and vertically from mother to fetus via the amniotic fluid (Diniz, 2017; Diniz et al., 2020; Batchtold, 2020; WHO, 2018; CDC, 2016). The *Aedes aegypti* is also the vector responsible for transmitting Yellow fever, Chikungunya and Dengue viruses (WHO, 2018).

It is estimated that 80 percent of Zika infected people were asymptomatic (Maestre, Caplivski and Fernandez-Sesma, 2016; WHO; 2018). For those that do present with symptoms, these may include, a “mild fever, rash, conjunctivitis (inflammation of the eyes), muscle and joint pain, malaise, and headache” lasting between two to seven days (WHO, 2018, p. 102). Importantly, these symptoms or lack thereof, make Zika a tricky virus to diagnose. Diniz (2017) suggests this was evident in the early days of the Brazilian outbreak which confounded scientists, medical professionals and the public as its clinical presentation is similar to Dengue and Chikungunya. The WHO (2018) identifies pregnant women and their fetus as being the most at risk in terms of suffering complications from Zika infection.

### 5.3.2 Zika, pregnancy and the risks to the unborn child

For most people, contracting Zika is uneventful, they are ill for a short time and recover fully, however for pregnant women contracting Zika can have severe consequences for their unborn child (Batchtold, 2020; Diniz, 2017; WHO, 2018). When a pregnant woman is infected with Zika she can pass this vertically to her fetus (Batchtold, 2020; Diniz, 2017; WHO, 2018). The WHO (2018) also reports that Zika has been found in breastmilk but argue that there is no clinical evidence supporting this as a viable mode of transmission. Current advice suggests the benefits of breastfeeding “outweigh the theoretical risk of Zika virus infection transmission



through breast milk” (WHO, 2018, p. 103.). The impact of Zika on the fetus is typically severe, leading to neurological complications, namely, Congenital Zika Syndrome (CZS) (Maestre, Caplivski and Fernandez Sesma, WHO, 2018). CZS describes a range of neurological complications including microcephaly and other congenital abnormalities, including, “preterm birth and death [and] Guillain-Barré syndrome [GBS]” (WHO, 2018, p. 103).

Microcephaly is typically diagnosed at birth with infant’s heads being significantly misshaped and much smaller than other babies of the same age and sex (WHO, 2018). Babies born with microcephaly typically suffer severe complications including, “brain calcifications, seizures, irritability, brainstem dysfunction such as swallowing problems, limb contractures, developmental delay, hearing and sight abnormalities, and other brain abnormalities” the severe nature of these disabilities means children require life-long care and therapeutic treatment (WHO, 2018).

Guillain-Barré syndrome (GBS) is a rare condition which attacks the immune system and peripheral nerves with symptoms ranging from mild to severe (WHO, 2016; WHO, 2018). In mild cases, symptoms are reported as weakness or tingling in the arms and legs or face, while severe cases can cause “paralysis of the legs, arms, or muscles in the face (WHO, 2018, p. 103). In 20% - 30 % of people, the chest muscles are affected, making it difficult to breathe”, speech, swallowing, hearing and sight are also impacted (WHO, 2018, p. 103). These symptoms make GBS a potentially fatal disease. Like microcephaly, GBS sufferers require life-long care and therapeutic treatment.

### 5.3.3 2015-2016 Zika outbreak in Brazil

On the 2<sup>nd</sup> March 2015, the Brazilian government notified the WHO that people were presenting with skin rashes in the north-eastern region of Brazil, in particular Recife (WHO, n.d). Between February 2015 and April 2015, some 7000 mild cases were reported but Zika was not yet suspected (WHO, n.d). Batchtold (2020) describes how the “alteration in epidemiological patterns of microcephaly and the cluster of cases” saw the Brazilian government declare an ‘Event in Public Health of National Concern’ (ESPIN) (Batchtold, 2020). At this point, the connection between Zika and microcephaly was still not established (Batchtold, 2020). Accepting a causal relationship between Zika and microcephaly, the WHO (n.d) declared the outbreak to be a ‘Public Health Emergency of International Concern’ (PHEIC) on the 1<sup>st</sup> February 2016, this was subsequently lifted on the 15<sup>th</sup> November 2016, lasting only 10 months (Batchtold, 2020). The WHO based the decision to lift the PHEIC on research which eventually established the link between Zika, and microcephaly together with the

acknowledgment that Zika now required a long-term approach (European Centre for Disease Prevention and Control, 2016).

According to Diniz (2017) and Batchtold (2020) the 2014-2015 Zika outbreak in Brazil was first thought to be a re-emergence of the already well-known epidemics that had long been present in Brazil, dengue and chikungunya, due to similarity in symptoms. It was a sharp rise in babies born with microcephaly in Recife that first alerted medical professionals to the possibility that there was another explanation to the illness they were seeing (Diniz, 2017). Moreover, at the time there was no scientific literature linking Zika to microcephaly (Diniz, 2017). It was only sometime later in November 2015, through the investigative work of local female doctors that vertical transmission of Zika from mother and fetus was identified and officially confirmed by the Brazilian Ministry of Health (MOH) (Diniz, 2017).

The *Aedes* mosquito is not new to Brazil (Batchtold, 2020). As previously mentioned, it is also responsible for transmitting other viruses; viruses which have long been present in Brazil and part of the country's history, particularly in impoverished areas which are most affected by vector borne viruses (Batchtold, 2020; Diniz, 2017). The exact method in which Zika came to enter Brazil remains unknown (Batchtold, 2020). According to scientific research, Zika "originated in western Africa [and] later spread (...) to the rest of the continent and into Asia (...) producing different phylogenetic lineages" (Diniz, 2017, p. 15).

#### 5.3.4 Zika prevention and control strategies

In the absence of a Zika vaccine and antiviral treatments the WHO, CDC and the Brazilian government favoured vector eradication measures (WHO, 2018). These focused on eliminating mosquito breeding sites, such as water collecting in rubbish, roof gutters, and other vessels, mass spraying of infected areas, and ongoing surveillance of mosquitos (CDC, 2016; WHO, 2018). There was also a strong emphasis on individual responsibility to prevent infection and transmission. For example, women in Zika affected areas were advised, where possible, to delay pregnancy for up to 2-years, men and women were also directed to use condoms (Batchtold, 2020; CDC, 2016; Diniz, 2017; WHO, 2018). Bite prevention measures included minimizing skin exposure through wearing more clothes, using insecticide treated bed nets and mosquito repellent (WHO, 2018). People in affected areas were also urged to close windows, use insect screens and air conditioning (WHO, 2018). Problematically, many of these suggested measures failed to consider and/or acknowledge the socioeconomic status of affected people or prevalent gender inequality issues in north-eastern Brazil (Batchtold, 2020; Diniz, 2017).

## 5.4 HIV/AIDS

### 5.4.1 A note on the epidemiological categorisation of HIV/AIDS

There is widespread disagreement as to whether HIV is an epidemic or pandemic. For example, McInnes (2016) claims that HIV “continues to be considered a single ‘pandemic’, despite widely varying means of transmission between different regions (and even countries in the same region)” (p. 384). Whereas, the WHO (2020b) categorises HIV as a ‘global epidemic’. McInnes (2016) argues that the varying modes of transmission across different regions means HIV is “better understood as a series of [context dependant] epidemics” (p. 384). For the purpose of this research, I elected to follow McInnes (2016) categorisation of HIV/AIDS.

### 5.4.2 Origin of HIV/AIDS

HIV is thought to have jumped from African chimpanzees to humans in south-eastern Cameroon, in one transmission event which Sharp and Hahn (2011) explain was the “principal cause of the AIDS pandemic” (p. 1). They describe how molecular epidemiological studies indicate a spread lasting between “50 to 70 years before it was recognized”; the likely epicentre of the pandemic is thought to be Kinshasa, the capital of the Democratic Republic of the Congo (DRC) (p. 15). In 1981 AIDS was recognised a new disease due to “increasing numbers of young homosexual men” who were presenting with “unusual opportunistic infections and rare malignancies” (CDC 1981; Greene 2007 as cited in Sharp and Hahn, 2011, p. 1). According to the WHO (2020b), there were an estimated 38.0 million people living with HIV at the end of 2019.

### 5.4.3 Pathogenesis and Clinical Presentation

Sharp and Hahn (2011) explain that “acquired immunodeficiency syndrome (AIDS) of humans is caused by two lentiviruses, human immunodeficiency viruses’ types 1 and 2 (HIV-1 and HIV-2)” (p. 1). Transmission can occur in a number of ways, commonly through the exchange of body fluids including, blood, breastmilk, semen and vaginal secretions (WHO, 2020b). It can also be transmitted from mother to fetus both during pregnancy and delivery. Once in the body, HIV attacks the immune system compromising defences against other diseases such as cancer and infections like pneumonia (WHO, 2020b). The weakening of the immune system is referred to as immunodeficiency which may take years to fully develop and materialise if untreated, at this stage an HIV patient has moved beyond having an HIV infection to the more advanced AIDS characterised by the development of “certain cancers, infections or other severe long term clinical manifestations” (WHO, 2020b, p. 2).

Patients presenting with HIV have different symptoms characterised by the stage they are at (WHO, 2020). Early symptoms are non-descript resembling a cold or the flu, it may take years for definitive symptoms to lead to a diagnosis (WHO, 2020b). Advanced symptoms that typically lead to a HIV diagnosis include, “swollen lymph nodes, weight loss, fever, diarrhoea and cough” (WHO, 2020b, pp. 2-3). Untreated HIV positive patients

may develop severe illnesses including, “tuberculosis (TB), cryptococcal meningitis, severe bacterial infections, and cancers such as lymphomas and Kaposi's sarcoma” (WHO, 2020b, p. 3).

#### 5.4.4 Prevention and treatment

There is no vaccine or cure for HIV, making prevention measures fundamental in HIV eradication aims (WHO, 2020b). These typically focus on minimising risk through individual responsibility and include, male and female condom use, getting tested for HIV if you are in a at risk group, knowing your HIV status, voluntary medical male circumcision (VMMC), using sterile drug injecting equipment and taking antiretroviral therapy (ART) if advised to (WHO, 2020b). Presently, HIV is managed through “antiretroviral drugs (ARVs)” which can both control the virus and help stem further transmission (WHO, 2020b, p. 2).

#### 5.6 Conclusion

This chapter has provided a brief descriptive overview of three biologically and socially complex epidemics, Ebola, Zika and HIV/AIDS. Focusing on their unique pathogenesis, clinical presentations and mainstream prevention and treatment pathways. It has highlighted some of the biomedical complexities around these epidemics and revealed some uncertainties and further research is ongoing specifically in relation to vaccine development highlighting the need for robust disease management. Whilst it is critical to understand diseases such as these in terms of how they impact the human body biologically, it is also critical to understand the social complexities around them. Specifically, the impact they have on marginalised women in the Global South. The following chapters analyse how these epidemics are thought about and responded to by the WHO and CARE.

## CHAPTER SIX: NARRATIVES OF DISEASE TO STORIES ABOUT PEOPLE

### 6.0 Introduction

The previous chapter provided a brief descriptive overview of three epidemics, Ebola, Zika and HIV/AIDS. In this chapter I build on Leach and Dry's (2010) argument that disease narratives are stories about people with purposes and consequences. I argue that even the most ostensibly safe stories about people including those grounded in alternative narratives can cause harm because contrary to the conceptual framework and my expectations, alternative narratives are not discrete and attributable to their widespread use, which appears to justify and reinforce outbreak and dominant narratives and their responses. As such, I suggest that all stories about disease affected people can inadvertently cause harm, including the disembodiment and ungendering of people and the construction of people as backwards, primitive, disempowered victims and agents of change. Importantly, stories such as these are particularly injurious for women, often leading to the exacerbation of gender inequality and what can be understood as the feminisation of health (FOH).

### 6.1 Ostensibly safe stories of disease

As expected, I found outbreak and dominant narratives deal with diseases and those affected in predominantly scientific and medicalised ways. Reflecting an epidemiological understanding of disease resulting in the construction of clinical, informative and compelling stories. Problematically, as anticipated, I found evidence that these stories often cause harm to disease affected people. A potent example of one such story is found in a descriptive account written by the WHO's Regional Office for Africa in which the 'hunt' for Ebola in the Democratic Republic of Congo (DRC) is chronicled.

Marie-Roseline Belizaire said "we have to go sometimes as far as 80 km from the coordination base, so in a day we can do 160 km." Today, in the company of one of her field supervisors, MarieRoseline is looking for a person who is the contact of a confirmed case of Ebola. The person has left his home and has gone to visit relatives in a remote corner of the Itipo area. The ride is dusty and hot. "The roads are not good so we have to be very careful. We go so slowly so it is as if we are walking, but walking with a motorcycle," said Marie-Roseline. At some point the road is so bad, Marie-Roseline and the field supervisor have to get off the motorcycle and start hacking their way through thick brush. Marie-Roseline said "This road is not very well defined. But this is what the supervisor, who knows very well the road, told me to take to reach the contact that we are looking for." In the end she learns the person she is trying to track down has returned home and she catches up with him in his village closer to central Itipo. She supervises a community agent as he takes the contact's

temperature and then double checks if he did it correctly. The contact is grateful for the surveillance team's persistence. Franck (pseudonym) Contact of Confirmed Ebola Case (Lingala) said "I went away for four days. They found me and took my temperature and it was normal." MarieRoseline and her team also regularly visit health clinics to check and see if they are getting any suspicious cases of people who have symptoms resembling Ebola. Tracing and then following all the contacts of confirmed and probable cases of Ebola is vital to controlling the outbreak (WHO, 2018, pp. 1-2).

In this vivid account we see characteristics of the outbreak narrative unfolding on the ground in which the epidemiological hunt for the source of the Ebola outbreak takes epidemiologists on a difficult journey into a remote, hard to reach African village. More than a disease narrative, it is a compelling story about Ebola affected people told from the perspective of those in positions of power and authority; legitimised by scientific and medical knowledge and expertise. By 'positions of power' I refer to the unequal relationship which exists between global health organisations and marginalised people, resulting in an imbalance of power which favours global health actors and their priorities and agendas. Problematically, the story frames these people in particular ways which suggests they are backwards, primitive and ignorant.

I found that even the most ostensibly safe stories about disease grounded in science and medicine can be harmful. Due to the ways in which "narratives – in constructing disease issues in particular ways – frequently also construct people and populations, labelling and making moral judgements about them" (Leach and Dry, 2010, p. 5). The construction of people predominantly occurs through the widespread use of potent disempowering language which frames people as backwards, primitive, ignorant and resistant. It also disembodies, un genders and oversimplifies gender which is particularly harmful to women. While I anticipated finding outbreak and dominant narratives doing this, I didn't expect alternative narratives to behave in the same way.

I expected to find alternative narratives behaving in ways which did not cause harm as suggested by the conceptual framework which identifies them as being different and discrete from dominant and outbreak narratives. Yet as I will come to show, they can be just as harmful because although they are different, they are not discrete narratives. Put another way, unlike the conceptual framework which suggests that alternative narratives are beneficial, I suggest that the problem lies not with a type of narrative but who controls the narrative and as Dry and Leach (2010) argue who gets to tell the story of disease and disease affected people. This conclusion leads me to suggest that there are no safe stories about disease when they are told by those in positions of power and authority, moreover, legitimised by scientific and medical knowledge and expertise.

Stories controlled by powerful global health actors have implications for affected communities and as I will illustrate in chapter seven, some of these stories exacerbate gender inequality and lead to the feminisation of health.

## 6.2 Stories about people and the implications

### 6.2.1 Stigmas: The backwards, the primitive, the ignorant and resistant

Disease narratives often deal with disease and disease affected people using certain kinds of language.

Problematically, this can inadvertently disempower, stigmatise and exacerbate inequalities for disease affected people. One of the most salient outcomes of disempowering language is the construction of disease affected people as backwards, primitive, ignorant and resistant, even when it is only implied, as exemplified here.

#### *Stories constructed from outbreak and dominant narratives*

It's been nearly twenty years since the residents of Bosolo village in northwest Democratic Republic of Congo have seen a car (WHO, 2018).

In mid-May, the brother of a man who was confirmed with Ebola stopped in the village to see relatives. He was a high-risk contact, who later died in the community without being tested because his family refused the Ebola test. So, the WHO vaccination team had to extend their vaccination ring to Bosolo village (WHO, 2018).

You have to cross four bridges; the path is very narrow and even on a motorcycle it's a nightmare. You have to be a very good driver," said Dr Ismaila. However, with the help of local residents, the WHO team was able to hack their way through the Equatorial forest. "We had to slowly open up a path for the vehicle together with the local people who helped cut down the branches," said Dr Fofana Thierno Oumar, WHO Ring Vaccination Team (WHO, 2018).

The Twa have a completely different culture. They shut off when they meet someone they don't know. There is a good chance they will just melt into the forest (WHO, 2018).

I thought it [Ebola] was just a rumour created by Westerners to stop us from eating bush meat (Palmer, 2014).

Like many others in his community, Aimee's grandfather Kambale, 53, didn't believe Ebola existed until he lost his wife to the disease (Shabeeb, 2018).

There is also strong resistance from local communities around vaccinations, healthcare inspections, or believing that Ebola is real (Shabeeb, 2018).

#### *Stories constructed from alternative narratives*

I thought it [Ebola] was just a rumour created by Westerners to stop us from eating bush meat (Palmer, 2014).

Like many others in his community, Aimee's grandfather Kambale, 53, didn't believe Ebola existed until he lost his wife to the disease (Shabeeb, 2014).

CARE are targeting rural communities to ensure the people are changing any harmful behaviour that could increase risk of infection and getting accurate messages from a source they can trust, so that myths circulating about the virus are eliminated (Frew, 2015).

During the early stages of the outbreak, there were many rumors circulating about the disease, like that Ebola was not real but was a conspiracy (Frew, 2015).

While stories such as these may capture the lived experiences and challenges of disease affected people, even in their own words at times, they are problematic. Constructing (implicitly and/or explicitly) a particular kind of story about people which locates them as backwards, primitive, ignorant and resistant to treatment. Moreover, they turn cultural practices and lifestyles into stories of deficiency and disease (Leach and Dry, 2010). Such stories can exacerbate gender inequality and lead to a feminisation of health (FOH). Importantly, constructing people in such ways even when it's implied, can reinforce the global myth that "Western science and medicine is modern and superior and therefore, better equipped to deal with epidemics" (Leach and Dry, 2010, p. 246). Stories such as these are not safe. Irrespective of the kind of narrative they affect how we think about and respond to people and they reinforce and exacerbate stigmas and inequalities because they are controlled and told by those in positions of power and authority. Stories of disease also disembodied.

#### **6.2.2 The disembodied**

Disembodiment occurs when stories reduce disease affected people to data points, pathogens, microbes, disease transmitters and victims, as exemplified below. One of the most salient and potent expressions of disempowering language and its disembodiment effects are found in the ways in which epidemiologists embedded in global health talk about people and disease.

The three breastfeeding mothers had confirmed Zika virus infection and were symptomatic within 3 days of delivery. Two of the three infants born of these mothers had confirmed Zika virus infection.



The Zika virus was detected in the breast milk of all three mothers and shown to be replicative in cell culture in samples from one mother (WHO, 2016, p. 2).

Mother-to-child transmission (MTCT) of HIV is a significant contributor to the HIV pandemic, accounting for 9% of new infections globally (WHO, 2017, p. 4).

Sexually active men and women are correctly counselled and offered a full range of contraceptive methods to be able to make an informed choice about whether and when to become pregnant, in order to prevent possible adverse pregnancy and fetal outcomes (WHO, 2016, p. 2).

A clustering of cases of fever and rash was detected in Brazil starting in February 2015 and these were confirmed to be caused by Zika virus in May 2015 (WHO, 2016, p. 4).

The emergence of the Ebola virus epidemic, like all other epidemics, puts a strain on the pillars of the health system that was already facing a number of challenges (WHO, 2018, p. 17).

CARE International is deeply concerned about a new Ebola virus outbreak in the North East of D.R.Congo, risking the lives of 300,000 Congolese. 37 cases, including 22 deaths, have been reported so far (CARE, 2018).

When diseases and people are talked about in such ways, complexity and humanity is lost. Disease affected people are constructed as pathogens, data points, disease transmitters, victims, problems and resources to be managed and contained as I will come to show. Disembodying disease from affected people exacerbates stigmas and inequalities leading to harmful outcomes for already marginalised people.

### 6.2.3 The oversimplified gender and the ungendered

Disease narratives typically deal with gender in two ways. Stories about disease affected people are ungendered and/or gender is oversimplified. Both have implications for disease affected people, shaping how we think about, and respond to them, which in turn can lead to the exacerbation of gender inequality. Of the two, gender oversimplification is perhaps the most common theme and the most potent and harmful way in which disease stories deal with gender.

#### *Oversimplify gender*

Gender oversimplification occurs when disease narratives fail to consider gender diversity between sexes, thereby suggesting that men and women experience disease in the same ways. It also occurs when disease narratives fail to consider differences within genders, suggesting that people who identify with a particular

gender also experience disease in the same kinds of ways. While the oversimplification of gender impacts both men and women, women are particularly affected due to their gendered roles as caregivers, their biological vulnerability to some communicable diseases, pre-existing gender inequalities and gendered assumptions. This is exemplified in the numerous statements which group women together as a homogenous body of victims, disease transmitters and caregivers. Problematically, when disease narratives deal with gender in such ways it can reinforce gender assumptions about women's roles, stigmas and exacerbate gender inequality.

Pregnant women should practice safer sex or abstain from sexual activity for at least the whole duration of the pregnancy (WHO, 2018).

Women who have had unprotected sex and do not wish to become pregnant due to concerns about Zika virus infection [should] have ready access to emergency contraceptive services and counselling (WHO, 2018).

The use of condoms by youth and rural people who engage in high-risk sexual activity is still relatively low however, and young women and rural youth are even less likely to know that using a condom can reduce the chances of HIV infection (CARE, 2012, p. 44).

Women are often those most affected as they are the caretakers of the ill in the family. They are the nurses (Jackson, 2015).

It is more common for women to be infected by Ebola since they are most often the primary caregivers of their spouses, children, and other females in the family. At least 56 percent of Ebola patients from this most recent outbreak are female (Shabeeb, 2018).

Recent media attention has highlighted how Ebola has hit women the hardest and how the epidemic is threatening gains in gender equality made in Liberia, Sierra Leone and Guinea (Lai, 2015).

75 percent of female deaths in Liberia (Lai, 2015).

While oversimplified disease stories fail to adequately acknowledge the different and disproportionate experiences between sexes and within genders, ungendered stories assume all people are the same and therefore experience disease in the same ways.

#### *Ungendered health narratives*

By ungendering I refer to the process of making gender invisible. Within the context of this research, it occurs through disempowering language and/or a lack of sex-disaggregated data and manifests in gender gaps in

health policy and interventions which are not gender sensitive. Like oversimplified gender stories, ungendered stories of disease reduce complexity and homogenise disease affected people into a corporate body of disease typically represented as statistics and data points. Irrespective of the vast diversity found in gendered experiences of disease, policies and interventions deal with disease affected people as a whole exemplified here in the ungendered ways in which disease is talked about.

Zero new HIV infections, zero HIV-related deaths and zero HIV-related discrimination in a world where people living with HIV are able to live long and healthy lives (WHO, 2016).

1/3 of all people with HIV/AIDS live in Southern Africa (CARE, 2010).

CARE International is deeply concerned about a new Ebola virus outbreak in the North East of D.R.Congo, risking the lives of 300,000 Congolese. 37 cases, including 22 deaths, have been reported so far (CARE, 2018).

Many people are moving between the borders on a daily basis. If we want to prevent another wave of deaths, precautions need to be taken urgently in both countries (CARE, 2018).

When stories about disease affected people are ungendered or gender is oversimplified it has implications for how people are thought about and responded to. Ungendered narratives are particularly harmful to women because they make gender invisible. Specifically, they make women's different and disproportionate experience of disease invisible. When the gendered dimensions of disease are invisible then policies will likewise fail to account for the gendered dimensions of disease such as how it impacts a women's socioeconomic status, care burdens, autonomy, access to health and SRH. Oversimplified gender narratives fail to consider the differences between women because they assume that all women experience disease in the same ways simply because they share a gender. Consequently, this shapes responses which are constructed on the assumption that all people experience disease in similar ways. Moreover, it can lead to women being problematised as a homogeneous group to be dealt with or leveraged off in the prevention, management and containment of disease. The implications of ungendered and oversimplified stories of disease will be considered more deeply in chapter seven in relation to the FOH.

### 6.3 Indiscrete alternative narratives

In accordance with the conceptual framework, I expected to find discrete alternative narratives marginalised within the data. However, I found indiscrete alternative narratives filled, both CARE and WHO policy. Far from being discrete, I found they were entangled with outbreak and dominant narratives and clustered around poor infrastructure, environmental issues and inequality, suggesting a complex, multi-scaled and multi-faceted

understanding of disease (exemplified below) opposed to a narrow understanding grounded in outbreak or dominant narratives as suggested by the conceptual framework.

Major epidemics of Zika virus disease may occur globally since environments where mosquitoes can live and breed are increasing due to recent trends including climate change, rapid urbanization and globalization (WHO, 2016, p. 7).

Almost a quarter of people in Lesotho are living with HIV. Food shortages – and the shortage of adequately nutritious food – have especially negative consequences for these people, as their medicines may not work properly. This can mean that they are less able to earn a living and pay for food. People living with HIV may be forced to make choices between feeding themselves and their families and continuing with life-saving medications (CARE, 2012).

Women are often those most affected as they are the caretakers of the ill in the family. They are the nurses (Shabeeb, 2018).

There are two possible explanations as to why alternative narratives are behaving in ways contrary to the conceptual framework hypothesis. First, the kinds of organisations they are embedded in mean that other ways of thinking about disease are acknowledged and considered. As a premier global health organisation, the WHO are mandated with “improving the health of all populations worldwide” (Kamradt-Scott, 2016, p. 402). This evolved to include an understanding that health is a precondition to peace and security which in turn sees them acknowledge a multitude of drivers of disease that undermine peace and security, such as climate change, poor infrastructure and inequality. Whereas, CARE in their capacity as an INGO have historic and well-established relationships with marginalised and poverty-stricken communities in many parts of the global south. These relationships together with their strong focus on alleviating social injustices and gender inequality means they are well positioned to understand on the ground complexities from local perspectives and incorporate these into how they talk about and respond to disease and disease affected people. Second, while alternative narratives appear to acknowledge the numerous complexities around diseases, including those grounded in marginalised perspectives, I argue that both the WHO and CARE use alternative narratives as potent stories for the purpose of reinforcing, justifying and legitimising predominantly western orientated policies and interventions. Therefore, I conclude that alternative narratives are not as discrete or as marginalised as the conceptual framework suggests.

### 6.3.1 Leveraging off the testimonial

Stories told about disease affected people by those in positions of power and authority share a common purpose which is the justification and reinforcement of predominantly western orientated disease narratives and interventions. This supports the notion that western interventions are superior and the best way to deal with disease (Leach and Dry, 2010). While all narratives explicitly and implicitly do this in some way, alternative narratives produce some of the most potent stories about people because they often contain first-hand accounts of disease affected people. For example, once such testimony is embedded within a CARE publication which recalls the story of HIV positive Ugandan widow and mother of 10, Florence Okello. In this potent testimony, Florence recalls how CARE's Savings and Loan Scheme has helped her and her children.

I joined a women's group run by CARE to save some money and use small loans to support my family. When your husband dies, you become very vulnerable. However, I was able to borrow money and pay it back slowly, at low interest. I've also bought a bicycle and a cow. Being part of the group helps in many ways. The savings and loans project has empowered me. I am able to raise income and look after my children. People don't want to help widows. We are forgotten. Now I look on the savings and loans project as my husband. It can provide for me when I work hard (CARE, 2010).

Florence's testimony is powerful and recounts her experience of HIV/AIDS and the difficulties she has faced. It also suggests that without CARE's Savings and Loan programme Florence and her children would suffer immensely. Whilst the project has certainly helped Florence and her family overcome some of the difficulties, she faced living with HIV/AIDS. It is the use of her testimony which is highly problematic. The reproduction of Florence's experience with CARE's Savings and Loan Scheme in a CARE publication both reinforces and justifies a predominantly western response which claims to deal with the implications of disease through addressing poverty, gender inequality and social injustices while empowering women. Stories such as these are some of the most potent and harmful because they invite the audience to "eat the trauma" of a marginalised woman and her children (Harman, 2020, p. 777). They also reduce people to programme outcomes including those which claim to 'empower' women yet as Kabeer (2017) argues, the "literature on the empowerment potential of microfinance has generated very contradictory findings and hence considerable controversy" (p. 652).

Although testimonials are valuable because they convey first-hand the lived experience of disease and appear to give marginalised people a voice, I suggest these are problematic when they are embedded in the meta stories of powerful organisations who leverage off testimonies in pursuit of their own agendas. Moreover,

leveraging off testimonies such as Florence's has broader implications for women because when testimonies are embedded in stories controlled and told by powerful global health actors it reinforces gender inequality and stigmas by emphasising victimhood while justifying the need for western orientated interventions.

#### 6.4 Conclusion

I have shown here that all disease narratives are foremostly stories about disease affected people with consequences and purposes often orientated towards reinforcing and justifying the agendas of global health actors. As expected, I found stories grounded in scientific and medicalised understandings of disease that deal with disease in particular ways which can inadvertently harm people through constructing them as backwards, primitive and resistant, thereby reinforcing stigmas. I also found that these stories also disembody, ungender and/or oversimplify gender. Contrary to the conceptual framework and my expectations I found that this was not limited to stories grounded in scientific and medicalised understandings of disease but also included alternative narratives which I found behaved in the same ways.

Moreover, I found that alternative narratives are not discrete or marginalised as suggested by the conceptual framework. They are often explicit and entangled with outbreak and dominant narratives; appearing to reinforce and justify western orientated responses. I expected to find merit in alternative narratives and a different way of understanding and addressing the many inequalities exacerbated by disease. Yet, I found alternative narratives can be just as harmful to people as outbreak and dominant narratives, particularly women. Therefore, I suggest there are no safe stories about disease affected people when they are told by those in positions of power and authority. In chapter seven I will consider more deeply the ways in which some stories about disease affected people can lead to the FOH and the implications for women.

## CHAPTER SEVEN: THE FEMINISATION OF HEALTH

### 7.0 Introduction

In the previous chapter I argued that disease narratives are foremostly stories about people with purpose and consequence. I suggested that there are no safe stories about disease affected people when they are controlled and told by powerful global health organisations. I found that all stories including those grounded in alternative narratives can inadvertently cause harm, especially for women. This chapter demonstrates the significance of the relationship between stories, global health, gender and women beginning with historical constructions of women in early public health followed by the construction of women in contemporary epidemics. This chapter then presents two fundamental ways that global health has made Ebola, Zika and HIV/AIDS a gendered problem for women to address. First, I will argue that an explicit agenda exists which seeks to 'empower' women in their gendered roles and instrumentalise these within western orientated interventions as a way to deal with disease. Second, I will show how global health actors reinforce and justify their interventions through stories which render women as helpless victims in need of interventions. Dealing with disease and disease affected women in these ways exacerbates gender inequalities and stigmas, leading to harmful outcomes for women and contributing to what can broadly be understood as the feminisation of health (FOH) or the implicit and/or explicit gendering and problematisation of disease.

### 7.1 Women, public health and the gendering of disease

#### 7.1.1 The construction of women in early public health

Literature is full of examples of the ways in which women are dealt with in public health, including early public health which often saw women treated in unfavourable ways. Early public health's treatment of women and gender is important to consider because it spills over into how they are dealt with during contemporary epidemics, such as, Ebola, Zika and HIV/AIDS. Here I provide an overview of some of the ways in which women have been constructed in the early years of public health. 'Construction' in this context, follows Leach and Dry's (2010) argument that the process of constructing disease narratives also constructs "people and populations, labelling and making moral judgements about them" (p. 5). The process of constructing women also disembodied them via the story told about them and/or their exclusion from the story. The treatment of women in relation to disease and early public health can be broadly categorised into the following two themes, the fallen women and the irresponsible women and mother. It is important to consider these early examples which illustrate how women were treated in public health because as I will show, these stories about women underpin and still inform how women are thought about and dealt with within the context of contemporary health and disease.

### 7.1.2 The disease carrier

Wald (2008) describes how early attempts to understand the origins of the North American Typhoid outbreak during the early 1900's established the relationship between the "identification of the healthy human carrier to the stories and history of epidemiology" (p. 26). The identification of Mary Mallon was significant because it confirmed the theory that healthy human carriers existed. Often unaware of their status, they "constitute a threat without knowing it" (p. 22). Consequently, to this day Mary remains the most called on case of the healthy human carrier, reflecting the potency of her story (Wald, 2008). Mary's case is particularly interesting and relevant to my research due to the way in which epidemiology, scientific authority and narratives came together to locate typhoid as a gendered disease through a moralistic narrative of which Dr Soper was a central figure to that end.

Wald (2008) describes Dr Soper as a "masterful storyteller" whose epidemiological investigation reads like a detective story. Like many others at the time, Dr Soper subscribed to the theory that a healthy human carrier could exist. This belief saw him feverishly pursue the yet unknown origin of the 1907 typhoid outbreak on Long Island, North America. He would eventually identify Mary Mallon, an Irish immigrant family cook as the healthy human carrier and superspreader (Wald, 2008). The identification of Mary sparked intense interest from media, science, and medicine; the latter sought Mary's cooperation for scientific research to establish the link between her and the outbreak, refusing she was incarcerated, and biological samples were taken without her consent; investigations would later attribute the outbreaks to other explanations which did not include Mary (Wald, 2008). Mary's refusal to cooperate, and the lack of an established link between Mary and the typhoid outbreaks, saw Dr Soper and his colleagues move to establish a "causal rather than coincidental" link (p. 71). Wald (2008) explains this was established through both "laboratory work and the epidemiological narrative of detection" and through employing "features of another, more familiar, story of contagion: the conventional melodramatic tale of venereal disease" manifest in the moralistic narrative of the fallen women (p.71).

### 7.1.3 The 'fallen women'

During the 1900's the prevalence of venereal disease threatened the integrity of "the family, the nation, and the white race" (Wald, 2008, p. 85). Wald (2008) describes the concern around venereal disease manifested in cautionary tales about 'types' specifically, the prostitute. Notably, these were also present in medical journals resulting in the construction of the 'fallen women' narrative which postulates that,

fallen women characteristically lacked proper supervision because she had immigrated or migrated to the city and has lived among temptations and without the benefit of friends or relatives. As the



story goes, she was often lonely and therefore easily persuaded to follow her heart. She could be led to her fall by her desire for luxuries she could not afford (Wald, 2008, p. 85).

Dr Soper drew on the popularity of the fallen women narrative and Mary's situation as a poor single woman who enjoyed the company of men as evidence that she was immoral. Thereby, "implicitly coding her disease as a result of her illicit behaviour"; ignoring the widely known fact that typhoid was not a sexually transmitted disease, and nothing suggested Mary was a prostitute or had a venereal disease (Wald, 2008, p. 84). Mary's situation and the popularity of the fallen women narrative along with Soper's scientific authority allowed him to establish the causal link he needed between Mary and the typhoid outbreaks. Consequently, Mary was dehumanised, vilified, and re-cast as 'Typhoid Mary'; the "most invoked symbol of the dangerous carrier of communicable disease from that time into the present" (Wald, 2008, p. 68). Like many epidemic superspreaders, patient zero and index cases, Mary was a "narrative device" which signalled "the effort to fashion an outbreak narrative" (Wald, p. 256). A further chapter in the construction of typhoid Mary occurred in 1915 when she was blamed for causing a second typhoid outbreak at the Sloan Hospital for Women. Importantly, this event added an additional narrative and saw all women's behaviour and morals fall into question, especially that of the housewife.

Mary Mallon was an innocent victim who was constructed as a 'fallen woman' through science and medicine who sought to explain her health carrier status. Her identity as a fallen women was reinforced because typhoid is a "disease associated with bodily excretions" which had the power to "evoke particular fear and disgust"; Wald (2008) claims that these feelings were displaced onto immigrant and migrant populations living in American tenements (p. 82), specifically, migrant and immigrant populations whose polluting bodily fluids were deemed a threat to national security, a national disaster. Understanding the role narratives play in constructing identity is important as the outbreak narrative and variations of it also construct people, communities and populations, in often detrimental ways (Leach and Dry, 2010; Wald, 2008).

#### 7.1.4 The irresponsible women and mother

When Mary was released from prison in 1910, she disappeared, only to re-emerge in 1915 "during a typhoid outbreak at the prestigious Sloane Hospital for Women, where she was employed as a cook" (Wald, 2008, p. 104). A condition of her release stipulated that she was not permitted to work as a cook again. Having broken this condition, and in full knowledge of her healthy carrier status, Mary was labelled not only a fallen woman, but a criminal (Wald, 2008). Whilst criticism was levelled at Mary for knowingly breaching her conditions some of the harshest criticism was levelled at housewives, revealing what Wald (2008) refers to as "*medicalizing the*

*gender menace*” (p. 104).

According to medical historian Judith Leavitt (as cited in Wald, 2008) all women were considered dangerous because all women were potential carriers, whether they had typhoid or not; moreover,

being a carrier was a gendered condition, one in part defined by sex-role expectations. As cooks, all women food handlers were potentially dangerous to the public health, whether they were employed outside the home or within it (p. 106).

Dr Soper also identified gender roles as the reason why women were disproportionately affected by typhoid, specifically the gendered role of caregiver and housewife (Wald, 2008). The latter drew harsh criticism from Dr Soper (Wald, 2008) who blamed housewives for failing to keep typhoid out of their homes through a lack of housekeeping diligence; namely, the hiring of the gendered role of cook which he claims was done with a lack of background checks (Wald, 2008). The emphasis on caregivers (specifically mothers) and housewives shifted focus away from actual modes of transmission (water contamination), thereby the “carrier state itself became gendered” (Wald, 2008, p. 106). Although both mothers and housewives were blamed for outbreaks, housewives were singled out as being responsible for keeping disease out of the home, thereby, feminising health through gender roles and responsibility.

Wald’s account of Mary Mallon is useful to my research because it exposes a historical, yet relevant link between gender roles, communicable disease, epidemiology and the power and authority of scientifically endorsed narratives. Importantly, it illustrates how narratives become powerful and persist when the one constructing the narrative occupies a position of power and authority, such as Dr Soper. Moreover, it reveals how these in turn may construct a feminisation of responsibility which I suggest, is a fundamental aspect of the feminisation of health. Interestingly, prior to Dr Soper’s identification of Mary it was widely believed that house flies were a typhoid vector illustrating another early example of feminising health via responsibility.

#### 7.1.5 The responsible wife and mother

One of the earliest (but not only) suspected ‘carriers’ of Typhoid was the common house fly. It was believed for a time that house flies were typhoid carriers and the onus was placed on housewives to deal with them, “with the advent of and wide-scale acceptance of bacteriology, housewives and screens were repeatedly enlisted in the campaign against what one report called the “simplest” health problem and the “least excusable” disease” (Wald, 2008, p. 80). This ostensibly innocent relationship between the common housefly and the housewife is one early example of the feminisation of health through responsibility. The gender role of housewife meant women were held responsible for the management of the typhoid carrying housefly. Scientific

and medical understandings of typhoid would eventually show that “all typhoid is traceable to polluted water” and not transmitted by houseflies (Adams as cited in Wald, 2008, p. 80). Problematically, the link was now established, cementing the role of housewife to the management of a disease vector.

Wald’s (2008) account of the early years of public health reveal valuable insights into the foundational relationship between women, public health and stories. This is important to consider because many of these assumptions about women remain today and inform how women are thought about and responded to in relation to contemporary health and disease. As I will illustrate in the following section, marginalised and disease affected women are still constructed in ways that both explicitly and implicitly locate them as deficient in some way and of questionable character. They are still largely deemed responsible for the prevention, management and containment of disease through their gendered roles, particularly that of caregiver and they are still labelled and stigmatised as carriers and transmitters of disease. Evident in the ways in which they are talked about and responded to by global health actors and their western orientated policies and interventions.

## 7.2 Contemporary epidemics: The visible women, the conspicuously invisible women, and the victim

As with early public health, contemporary global health also deals with women in particular ways often causing harm, constructing them according to their gender and sex. As previously illustrated, global health exacerbates gender inequality through targeting SRH while failing to consider the social drivers of disease which exacerbate gender inequality. Here I will provide nuance through illustrating how global health deals with women in particular ways, namely, rendering them helpless victims, visible yet invisible, and/or are altogether missing at every point, including policy, programming, and data. The way in which contemporary global health deals with women can be broadly understood through examining Harman’s (2016) argument that a “central paradox exists in global health governance: the conspicuous [or visible] invisibility of women and gender” (p. 526).

### 7.2.1 The paradox in global health governance: The conspicuous invisibility of women and gender

Harman (2016) argues that there is a “central paradox in global health governance: the conspicuous invisibility of women and gender” (p. 524). Using a case study of the West African Ebola outbreak of 2014, Harman (2016) argues that women were conspicuously invisible at every point in global health governance.

Other than a handful of high-profile women leading global institutions, women are conspicuously invisible in global health governance: people working in global health are aware of and see women in care roles that underpin health systems, yet they are invisible in global health strategy, policy or practice. Women are only made visible through motherhood. The problem here is not only the

conspicuous invisibility of women but that of gender, as global health policy and practice ignores and subsequently reinforces gendered norms of care and social reproduction (Harman, 2016, p. 524).

Using the 2014 West African Ebola outbreak as an exemplar, Harman (2016) identifies two distinct ways in which women and gender are treated in contemporary global health governance; a select few women are made 'visible' through their high-profile positions in governance while the majority are conspicuously invisible. In this chapter I show how narratives of women were created to varying degrees, in epidemics such as Zika and Ebola.

### 7.2.2 The visible women

A salient example of the 'visible' women is found in HIV/AIDS governance. Harman (2011) argues that "women occupy positions at every level of HIV/ AIDS governance, from the Director of the World Bank's Global HIV/AIDS Programme, through to the front line of community aid workers" (p. 214). Reflecting a trend which seeks to add a gender dimension through inclusion. Notably, she argues that "female inclusion within governing bodies has been prioritised by international organisations, states, and communities as a means of including gender in policy planning and implementation" (p. 214). While the inclusion of women in health governance bodies such as those which address HIV/AIDS appears to promote gender issues she warns that it is often nothing more than tokenistic inclusion resulting in no real power, therefore, it has not resulted in better outcomes for HIV/AIDS affected and impacted women. I will elaborate further on the inclusion of women in disease governance and the implications therein in a later discussion around the politics of absence. While some women are 'visible', most women's experience of disease remains conspicuously invisible. This is particularly evident in the female centric care economy.

### 7.2.3 The conspicuous invisibility of women and gender in the care economy

Harman (2016) describes the care economy as a,

feminised burden (...) [which] can be explained by the gender norms and expectations of women as a gender with regard to social reproduction in the family and wider communities in which they live (p. 525).

The feminised burden of care is arguably the most salient way women and gender are rendered conspicuously invisible in health. It is also the way in which women experience the most harm through the exacerbation of gender inequality and stigmas which see their workloads increase exponentially. As previously mentioned, this occurs because global health governance "ignores and subsequently reinforces gendered norms of care and social reproduction" (Harman, 2016, p. 524). Similarly, Smith (2019) also notes that within the context of health system strengthening (HSS), and disease outbreak policies and preparedness, gender is only considered in

relation to “maternal and child health, reflecting assumptions that women are solely responsible for reproductive and family health” (p. 361). The way in which global health governance treats women and gender reveals gender gaps in policy. Smith (2019) argues that

analysis of global-level policy documents related to disease outbreaks reveals a notable lack of gender analysis. There is no mention of gender inequality, women’s particular needs, or ensuring the health of marginalised groups, in most high-profile policy documents (p. 358).

Moreover, she accuses those in global health of having an “unspoken agreement” that “gender is not relevant to global-level processes” demonstrable in gender gaps across policy documents, problematically, she points out that global policy impacts local health outcomes (pp. 365-366). This is particularly detrimental for women who are “invisible to the institutions and policies that design and implement global health strategies” (Harman, 2016, p. 526). Harman (2016) claims that during Ebola “the differing impacts of the disease on women and men, the gendered role of women as carers, and the role of women in health systems” were invisible at every point of the international response including, but not limited to, data around transmission and death rates, a lack of “discussion on gender as an analytical lens in the emergency and long-term response” and the lack of “discussion as to the role of social reproduction and women in the care economy in strategies to strengthen health systems (pp. 524-525). Problematically, the conspicuous invisibility of gender exploits women’s gendered roles, particularly caregiving, which can lead to the exacerbation of gender inequality and the reinforcement of stigmas. Moreover, Harman (2016) warns that rendering women and gender conspicuously invisible in the informal care economy

may have direct impacts on women’s health – as primary carers and first responders to people sick with highly infectious diseases such as Ebola – and indirect impacts on ill health of women from the burden of care, employment and family responsibilities (p. 534).

Although women's roles as caregivers are seen and acknowledged by those working in global health, it does not equate to policies and programmes that are gender sensitive. Instead, women’s gender role of caregiver is exploited and instrumentalised to fill gaps in weak health systems (Anderson and Beresford, 2016; Harman, 2011; Harman, 2016). Likewise, the presence of *visible* women within global health governance also does not guarantee or necessarily result in better outcomes for women, it may in fact exacerbate gender inequality (Harman, 2011). In other words, women and gender in global health governance are visible yet invisible at every point, including how they are differently and disproportionately affected by disease socially, biologically

and in their gendered roles as caregivers. All of which can lead to the exacerbation of gender inequality and stigmas and what can be understood as the feminisation of health. Harman's (2016) identification of the conspicuous invisibility of women within global health is not confined to Ebola, it is also evident in both Zika and HIV/AIDS through the gendered role of caregiver which is typically leveraged off to support weak health systems and exploited by various actors including those within the community. Moreover, when women and gender are considered, it is often based on assumptions about their autonomy and access to health care. Their experiences are also homogenised through a lack of consideration and/or acknowledgement of diversity amongst women across social and/or geographic contexts. This was particularly evident during the 2014-15 Zika outbreak in Brazil where elite women were able to leave Zika infected areas to continue their pregnancy in safety and access high quality SRH health care, an option not available to poor women (Batchold, 2020; Diniz, 2017; Harris et al., 2016). Together, these and many other factors which I suggest will emerge in the data, point to the FOH; being the implicit and/or explicit gendering and problematisation of disease both biologically, socially, and economically.

#### 7.2.4 The helpless victim

One of the ways in which contemporary health deals with women is to characterise them as a marginalised, helpless body of victims in need of interventions (Harman, 2011, p. 222). For example, Nunes (2016) suggests that the processes that framed Ebola also saw "certain groups" labelled helpless victims; "anonymous faces arousing momentary pity, distant others in wretched lands, reiterations of a familiar story of 'African despair' (pp. 550-551). Specifically, women and gender are predominantly talked about in terms of "vulnerable risk" due to their gendered role as mothers, maternal needs, and the needs of their infants (Harman, 2016, p. 529). Problematically, Harman (2011) suggests that the "focus on vulnerability obscures any wider understanding of the presence of women within HIV/AIDS governance and activity" (p. 222). The location of women as victims also has implications for men. Harman (2011) suggests that women's victimhood within the context of HIV/AIDS, is synonymous with notions of female emancipation from men's "polygamous, violent, and sexist behaviour" their "relationships and familial constraints" (p. 222). Problematically, she warns that by framing women as victims two things occur, first, women are "seen as passive recipients of international aid" which she states is not the reality (p. 222). Second, she warns that framing women as victims in relation to men detracts from the 'feminisation of HIV/AIDS' by "including [both] men and women" in the discussions of vulnerability and victimhood. The feminisation of HIV/AIDS refers to the disproportionate "number of women infected and affected by the epidemic" compared to men in "biomedical and social terms" (Harman, 2011, p. 213). Moreover, zeroing in on vulnerability "obscures any wider understanding of the presence of women within

HIV/AIDS governance and activity” (Harman, 2011, p. 222) where roles of power are typically aligned with “neo-classical household models” (Bedford, 2008, as cited in, Harman, 2011, p. 222). Instrumentalising women as victims through leveraging on notions of vulnerability, feeds into the politics of presence which I will later discuss, specifically, how it shapes the ways in which women are added to disease governance at the local and global level.

### 7.3 Narratives of women from WHO and CARE

#### 7.3.1 The ‘empowered’ women

As expected, I found an explicit and salient agenda across the data which seeks to empower women in their gendered roles as a way to deal with disease. There is a clear assumption and expectation in global health that women are the best resources, once *empowered* in their gendered roles, to deal with disease and the implications. Problematising disease as a gendered issue is linked with neoliberal ideologies and gender mainstreaming initiatives in global health which see women added to governance bodies as a way to meet donor requirements around policy and programming, thereby formalising women’s responsibility to deal with disease (Gupta et al., 2019; Harman, 2011).

The empowerment of women and girls at all levels of society is the main way of preventing HIV more effectively. This is the central concern of CARE Austria (CARE, 2010).

Empowering people with the ability to bring themselves through crises like the Ebola outbreak is at the heart of CARE’s work. The VSLA groups, for instance, provide people like Nyonblee with access to financial services that helps them save their money and kick start a stable income, which in turn makes them less vulnerable to natural disasters and health crises (Frew, 2015).

If it is accepted that health begins with health workers, their empowerment is necessary on a general basis (WHO, 2018, p. 50).

A key community to empower during outbreaks are healthcare workers, and volunteers [typically women] who are often the frontline responders (WHO, 2018, p. 39).

Although some of these examples are ungendered, CARE’s organisational focus on women and the disproportionate number of women in the formal care economy strongly suggests that it is women and not men who require empowerment. Whilst notions of empowering women as a way to deal with disease appear to advance gender inequality issues, I argue that it is highly problematic and harmful. First, advocating for the empowerment of women assumes and reinforces notions that women are not empowered in the first place.

Second, it establishes empowerment as something that is not intrinsic to women but is bestowed upon women and legitimised by powerful and authoritative western global health actors. Moreover, a woman's empowerment is thus conditionally tied to her ability to successfully instrumentalise her gendered roles in the prevention, management and containment of disease of which she is increasingly made responsible. Making women responsible for disease through 'empowering' them resonates with Chant's (2008) argument that responsibility is increasingly feminised due to a growing trend in which women's work burdens are increasing outside the home, including "performing the bulk of unpaid reproductive tasks for husbands, fathers, brothers and sons" (p. 178).

I also found that empowerment was also explicitly linked with global health obligations around addressing human rights and gender equality issues, similar to the shift towards empowering women in Goal 5 of the Sustainable Development Goal's (SDG) (Davies and Bennett, 2016; Smith, 2019).

A woman-centred approach is underpinned by two guiding principles: promoting human rights and promoting gender equality (WHO, 2018, p. 5).

Their [health workers] voice, rights and responsibilities must play a central role in developing and implementing solid policies and strategies towards universal health coverage (WHO, 2018, p. 50).

I have shown here that an explicit agenda exists within global health which seeks to empower women and their gendered roles as a way to deal with disease. Underpinning this agenda are obligations around human rights as per SDG goal 5, gender equality and gender mainstreaming as well as neoliberal ideologies which locate women as resources. Whilst notions of empowerment appear to advance gender equality, I suggest it is acutely detrimental for women and gender equality because it reinforces the feminisation of responsibility through instrumentalising women in the prevention, management and containment of disease.

### 7.3.2 Instrumentalising women

As expected, I found the instrumentalization of women and their gendered roles in the prevention, management and containment of disease was explicit and throughout the data.

It is important for the international community, governments, and relevant stakeholders to deliberately focus on women as valuable agents of change and social mobilizers with a central role to play in shaping a comprehensive and multi-faceted response system, sharing expertise and knowledge, raising awareness and enhancing care. Women must be included in strategizing when assessing the scope of the outbreak and designing responses and implementing interventions. It is



critical to recognize and involve women as leaders in their communities. Women may have increased exposure to the disease, but they are also the best resources for containing it. They must be meaningfully engaged in raising awareness and planning responses in their communities and countries (Lia, 2015).

In this example we clearly see women being constructed as 'valuable agents of change' and the *best resources* to deal with disease, reflecting neoliberal agendas around the instrumentalization of women's gendered roles as a way to deal with problems. The implications of targeting women and their gendered roles and treating them as resources and agents of change manifests in the sharp and significant increase in women's work loads, namely care burdens. Analysis across all three epidemics considered in this study revealed that while it is widely understood in global health that women disproportionately carry the enormous formal and informal care burden associated with these diseases on top of their already substantial workloads they are still targeted and instrumentalised as a way to deal with disease.

There is little doubt that women are at the frontline of the Ebola response as they are caring for sick relatives at home, or likely to be working as nurses, traditional healers and health facility cleaners (Lai, 2015).

While I expected to find women and their gendered roles being instrumentalised in the prevention, management and containment of disease, I did not expect to find that it took precedence over their wellbeing, particularly their significantly increased risk of transmission through exacerbated care burdens.

Women may have increased exposure to the disease, but they are also the best resources for containing it (Lia, 2015).

It is more common for women to be infected by Ebola since they are most often the primary caregivers of their spouses, children, and other females in the family. At least 56 percent of Ebola patients from this most recent outbreak are female (Shabeeb, 2018).

I found that western orientated interventions rely heavily on women and their gendered roles to deal with disease, irrespective of the widespread understanding in global health that women already suffer gender inequality in the care economy and experience an associated increased risk of transmission. The second way global health deals with women is through perpetuating culturally and socially constructed assumptions that victimhood is gendered, arguably for the purpose of reinforcing and justifying western orientated interventions.

### 7.3.3 The disempowered victim

Global health actors seek to justify, reinforce and legitimise western orientated interventions through the stories they tell about disease (Leach and Dry, 2010; Leach, Scoones and Stirling, 2010). None is more potent than the disempowered female victim. As anticipated, I found numerous iterations of this kind of story throughout the data.

She [Nadej] made it out alive and with a better understanding of Ebola, but her return home presented new problems. Her husband, a farmer and the family's sole provider, abandoned Nadej and their children when he learned of her diagnosis (Shabeeb, 2018).

They [women] are poor and often live in communities with poor sanitary conditions which are ideal for this type of mosquito. And they have the least access to comprehensive sexual and reproductive health services, at a time when they need it most (CARE, 2016).

Men were luring the young girls away for a few days of unprotected sex. The girls are then returning with money or food stocks and resuming household tasks. However, many months later these young women are discovering they are pregnant but cannot identify their sexual partners and are often stigmatized by the community and family members as they cannot be culturally cleansed through marriage (CARE, 2016, p. 7).

With the onset of the drought, many families have used child marriage as a coping mechanism to raise income (through payment of a bride price) or to reduce the number of dependents per household. This increase in child marriage has left many girls at risk of sexual and physical abuse, poor nutrition and increased chance of maternal neonatal death (CARE, 2016, p. 6).

I returned home from the hospital and to an empty house. We had no clothes, all our belongings were burned. How could we survive? I could only think that we cannot live anymore (CARE, 2014).

While such accounts as exemplified here provide valuable insights into the lived experiences of women affected by disease it disempowers them when they are embedded into larger stories controlled and told by those in positions of power. As previously shown in chapter six, these kinds of stories invite the audience to "eat the trauma" of marginalised women thereby reinforcing stigmas (Harman, 2020). Moreover, constructing women as disempowered victims suggests that they are in some way deficient and emphasizes the assumption that victimhood is predominantly a female attribute.

#### 7.4 Conclusion

As expected, I found the instrumentalization of women and their gendered roles in the prevention, management and containment of disease was explicit and throughout the data. I found a relationship between notions of empowerment, the instrumentalisation of the gendered role of caregiver and the construction of women as disempowered victims which seemingly appeared to reinforce, justify and legitimise western orientated interventions.

I found that global health has an explicit agenda to empower women, guided by human rights, gender equality and gender mainstreaming objectives. I have suggested that there is a link between the agenda to empower women and the instrumentalisation of their gendered roles of caregiver as a way to deal with disease, irrespective of increases in workloads and risk of transmission. Furthermore, I found that women were often portrayed as powerless victims. These kinds of stories reinforce assumptions that women are powerless and have no agency. When global health deals with gender, women and disease in these ways it exacerbates gender inequality through reinforcing and legitimising gendered assumptions and stigmas. It also over burdens women's already disproportionate care burdens and exposes them to an increased risk of contracting disease.

## CHAPTER EIGHT: DISCUSSION AND CONCLUSION

### 8.0 Introduction

Within the context of COVID-19 desktop research which uses secondary data is increasingly becoming a viable option and the reality for many researchers including myself, particularly, when the possibility of doing field research and primary data collection is severely restricted and/or impossible. It is my hope that this thesis has illustrated the value of robust policy related research through showing that engaging with secondary data in a critical way can yield valuable and insightful outcomes. Using desktop policy-based research I have sought to address the overall research question which asked 'In what ways do narratives construct contemporary epidemics and the responses? What alternative narratives are marginalised, and what are the implications for women at the margins of society when health is feminised?' To help answer this question I posed three sub-questions. This chapter revisits the research questions beginning with a summary of the key arguments and findings. It then discusses the limitations of this research, possibilities for further research, concluding with my final thoughts.

### 8.1 The feminisation of health: Women as a 'resource'

I began this thesis by suggesting that the feminisation of health can be understood as the implicit and/or explicit gendered problematisation of disease. Gendered problematisation of disease refers to the ways in which global health has made disease a women's problem to deal with. A review of key literature in chapter three highlighted the often-explicit ways in which global health has instrumentalised women and their gender roles in the prevention, management and containment of disease. The outcomes of this often led to the exacerbation of pre-existing gender inequalities, specifically, an increase in women's already heavy care burdens in both the formal and informal care economy. My research confirmed that global health's treatment of women as a resource is both ubiquitous and explicit and highlighted global health's uncritical adoption of the feminisation of responsibility and obligation, which Chant (2008) argues signals a turn from the feminisation of poverty towards the feminisation of care practices. Global health's uncritical adoption of the feminisation of care practices is explicit in the ways in which women and disease are constructed in narratives or stories of diseases, subsequently shaping programmes and policies which explicitly instrumentalise women as 'resources', and in doing so, exacerbate gender inequality. Whilst the feminisation of health can be described as the gendered problematisation of disease, I now conclude that the feminisation of health is best understood as the persistence of a gender-based assumption within global health about women.

### 8.1.1 A persistent gendered assumption

Global health's uncritical adoption of the feminisation of feminised practices of care as a way to deal with disease is rooted in a persistent gendered assumption about women. Specifically, the historic and ongoing belief that empowered women are best placed to deal with disease due to their gendered role as caregivers, contrary to the findings of numerous studies which clearly show that women experience the adverse effects of disease differently and disproportionately to men.

The persistence of the gendered assumption about women can be attributed to two key agendas in global health. First, an agenda which explicitly seeks to instrumentalise women's gender role of caregiver to fill gaps in weak health systems (Anderson and Beresford, 2016; Harman, 2011; Leach and Dry, 2010; McInnes, 2016). This reflects a broader neoliberal ideology in which development was gendered under the guise of empowering women as a way to deal with structural inequalities created by aggressive neoliberal structural adjustment policies introduced during the 1980s global financial crisis. Chant (2016) argues that during this time the "efficiency rationale for 'engendering' development policy became increasingly discernible" and the gendered role of women was linked with poverty alleviation and "female empowerment" (Chant, 2008). The feminisation of responsibility and obligation emerged from Chant's (2008) criticism of her own concept of the feminisation of poverty and its policy uptake which had a narrow focus on economic disparities between men and women rather than a more nuanced understanding of the multi-dimensional nature of gender inequality. Second, the persistence of gendered assumptions about women can be also attributed to global health's uncritical adoption of the concept of empowerment.

### 8.1.2 Global health's uncritical adoption of 'empowerment'

The uncritical adoption of empowerment serves an agenda in global health which seeks to deal with disease through 'empowering' women whilst justifying, reinforcing and legitimising western orientated policies and interventions. Though empowerment can advance gender inequality, I found that there are fundamental problems around the conceptualisation and use of empowerment in global health. I have argued that empowerment which originates with, and is informed by, powerful global health actors and neoliberal ideologies, is particularly injurious for women. I suggested that the kind of empowerment offered to disease affected women by global health does not advance gender equality because it first assumes that women are disempowered. Moreover, it diminishes and/or ignores how women understand and contextualise their own empowerment. An uncritical adoption of empowerment is problematic and contentious especially when the ones conceptualising and offering it are powerful global health actors with their own agendas to materialise. The problems around an uncritical adoption of empowerment are highlighted by Kabeer's (2017) study of

women's economic empowerment in Bangladesh. In which she argues that the notion of disempowerment relies on how empowerment is first conceptualised. Kabeer (2017) also identifies how the "adoption [of women's empowerment] by a diverse range of actors, including microfinance organisations, has given rise to a plethora of definitions that have gradually neutralised its original political edge (p. 650). Kabeer, Mahmud, and Tasneem (2018) argue that "conflicting views" reflect numerous "differences in the conceptualisation of empowerment" (pp. 235-236). For example, they claim that "corporations, donors and NGOs are now focused on improving women's access to paid work as the fundamental driver for achieving [economic] (...) empowerment", and in so doing, they draw on the work of Liberal, Marxist and feminist researchers who "argued that paid work contributes to women's empowerment" (Kabeer et al., 2018, pp. 235-236). Conversely, they suggest that there are "negative assessments" of empowerment which highlight the necessity of engaging in tenuous and difficult work to survive, in so adding to their already heavy work burdens (p. 236).

Kabeer's insights into empowerment raises questions, such as who gets to define empowerment and therefore disempowerment and for what and whose purpose does it serve to empower a particular group, namely marginalised, disease affected women? I have argued that Global health's agenda to empower women is explicitly linked to achieving desirable programme outputs. I have also argued that empowerment is conditionally linked to a women's ability to instrumentalise and perform her gendered role of caregiver in the prevention, management and containment of disease. Contrary to global health's often stated intentions around improving gender inequality through empowering women, I found gender inequalities are exacerbated, specifically care burdens, risk of transmission, socio-economic disparities and stigmas. Although there are many problems around global health's uncritical use of empowerment, there is value in the concept.

Kabeer (2017) suggests that empowerment can be understood as "processes of change" through which "those who have been denied the capacity for choice gain this capacity" (p. 650). Moreover, she describes empowerment as an increase in one's

capacity to make strategic and meaningful choices by those who have previously been denied this capacity but in ways that do not merely reproduce, and may indeed actively challenge, the structures of inequality in their society (p. 651).

For example, within the context of Bangladesh, Kabeer et al. (2018) "conceptualized [women's economic] empowerment in terms of changes that went 'against the grain' of the structures of patriarchal constraint" (p. 238). Therefore, real empowerment can be understood as enlarging a woman's capacity to choose for herself and her family those things which enrich her life. However, as Kabeer (2017) argues, 'choice' must be qualified

to “make it relevant to the analysis of women’s empowerment” (p. 651). The kind of empowerment offered by global health does not enlarge a women’s capacity to make “strategic and meaningful choices” because it is conditionally tied to specific programmes, policies, interventions and desired outcomes, thereby confining her ‘choice’ to a set of predetermined parameters defined by global health actors. In conclusion, global health’s uncritical adoption of empowerment as a way to deal with disease is grounded in a persistent gendered assumption about women, one of the fundamental reasons this assumption persists in global health is due to the way in which narratives work to consolidate assumptions.

## 8.2 Alternative narratives from the WHO and CARE: Complicit in constructing the feminisation of health

The gendered problematisation of disease and subsequent exacerbation of gender inequality, is largely attributable to potent scientific and medicalised stories told by global health actors. Underpinned by a persistent gendered assumption that empowered women are the best resource to deal with disease. The persistence of this assumption can be ascribed to the consolidating effect of narratives. Specifically, the alternative narratives embedded in global health which are particularly complicit in consolidating this assumption. Moreover, it is not surprising that narratives have a consolidating effect when they are controlled and told by those in positions of power and authority such as the WHO and CARE.

Narratives embedded in the WHO and CARE are very potent and contextualise disease and disease affected people in particular ways often leading to harmful outcomes, particularly for marginalised and disease affected women. Alternative narratives or stories are not distinct from outbreak and dominant narratives they work to reinforce, justify and legitimise them. Therefore, they do not offer other ways of thinking about disease and disease affected people as the conceptual framework suggests they might. The ways in which alternative narratives function in global health raises questions around their place in global health. I find they fail to offer so-called alternative ways of thinking about and responding to disease and those affected. The predominant factor which renders them ineffective and dangerous is their lack of independence being controlled and told by powerful global health actors. Essentially, like outbreak and dominant narratives, so-called alternative narratives are just as complicit in constructing the feminisation of health and consolidating assumptions about women.

## 8.3 Limitations

Working with secondary data was challenging and is one of the limitations which may have affected the findings of this research. While there are numerous advantages of working with secondary data such as time efficiency, cost and data quality, there are many challenges as well. These include a lack of familiarity with the data which

takes time for the researcher to overcome (Bryman, 2016). The time constraints of a master's thesis make achieving familiarity with the data difficult. Secondary data challenges also saw me reduce the number of organisations from an initial five down to two as there was too much data to manage in the time frame. This narrowed focus on two organisations may affect my findings. A further limitation occurred around selecting the policy documents to analyse because many were undated and/or live documents that excluded them from my research. Limitations also existed around interpreting some of the secondary data collected for this research due to its scientific and medicalised terminology being written for those in the field of public health which sits outside my academic background. Finally, working with narratives as long texts, not just phrases, requires detailed nuanced analysis that falls outside usual social science analysis and tools, like NVivo - this is why chapter seven is relatively short - presenting the full analysis would have meant exceeding the size of a MA thesis.

#### 8.4 Revisiting the conceptual framework

The conceptual framework guiding this research incorporated Wald's (2008) outbreak narrative approach and Dry and Leach's (2010) narratives and pathways approach to help identify the ways in which global health deals with disease. Thereby, providing a way to begin to understand how gender inequality is exacerbated by global health policies through the way women and gender are dealt with during epidemics such as Ebola, Zika and HIV/AIDS. Using the conceptual framework, I was able to identify outbreak and dominant narratives within global health which constructed disease and disease affected people in predominantly scientific and medicalised ways which in turn, lead to the exacerbation of gender inequality.

While the concept of outbreak and dominant narratives was useful, alternative narratives complicated the conceptual framework; they did not function as the conceptual framework suggested they would, revealing two significant points of tension. First, the conceptual framework suggested that alternative narratives are discrete and marginalised in global health. Yet, I found them to be explicit and often entangled with outbreak and dominant narratives. Second, I found that rather than providing different ways of thinking about disease and disease affected people grounded in perspectives outside of global health, they reinforced, justified and legitimised outbreak and dominant narratives. This reaffirms long held notions that Western knowledge systems and interventions are superior. This was particularly salient in the frequent and explicit use of the personal testimonies of disease affected women to justify, reinforce and legitimise western orientated interventions. Examples like this undermine the claim that conceptual frameworks formed by alternative narratives could inform and lead to better outcomes if they are given space in global health to sit alongside



outbreak and dominant narratives, because they were given space yet they did not function as the conceptual frameworks suggest they should. This further undermines their legitimacy as providing different ways of thinking about and responding to disease. These problems disrupted and complicated the conceptual framework, yet they also revealed some interesting findings about how stories function within global health and the outcomes for marginalised women when their stories are controlled and told by global health actors. These problems with the conceptual framework led me to conclude that when alternative narratives are controlled by and told by powerful global health actors they do not and cannot function as the conceptual framework suggests they can. There are no alternative narratives within global health, and nor can there be, I suggest they can only exist outside global health.

The conceptual framework guiding this research suggested that contemporary epidemics are primarily understood through western orientated outbreak and dominant narratives. It suggested that this would also shape how disease affected people are thought about and responded to. Research around Ebola, Zika and HIV/AIDS revealed this to be the case. All three epidemics were fundamentally constructed through outbreak and dominant narratives. I also found that this shaped people in particular ways and led to western orientated interventions.

### 8.5 Further Research

As the world comes to terms with COVID-19 and warnings around the realities of future pandemics circulate, it is critical that further research is done to better understand the impacts western orientated interventions have on marginalised women in the Global South. It is clear that when complex health crises strike it is women who experience the outcomes differently and disproportionately. Further research is needed to examine the role of global health in exacerbating gender inequality and how this might be mitigated through more locally informed and controlled responses that do not overburden women. Further research is also needed to examine how alternative narratives can stand on their own and function in meaningful ways that do not reproduce, reinforce and justify global health agendas, beginning with asking questions around who has the right to tell other people's stories as raised by Harman (2011). Research is also needed to help understand why marginalised women in the Global South seemingly embrace Western notions of 'empowerment' (as reflected in their personal testimonies), particularly within the context of global health interventions which often result in women being overburdened with responsibility.

### 8.6 Final thoughts

I initially thought and hoped that alternative narratives might provide a way to deal with gender inequality if they were given space within global health to sit alongside outbreak and dominant narratives as suggested by

the conceptual framework. Despite my optimism, I concluded that the problem is more complex than simply creating space for alternative narratives and their subsequent interventions. It is also bigger than problems around the kinds of disease narratives used in global health, whatever form they take. I suggest the fundamental problem lies in the ways in which global health and its powerful actors view women and their gendered roles as resources informed by gendered assumptions about women, neoliberal ideologies and the power dynamics at play in global health agencies. Therefore, the problem is fundamentally one of persistent gendered assumptions, ideology and power and the narratives or stories of disease they produce and legitimise. Stories which are embedded in and reproduced in global health, ultimately leading to the exacerbation of gender inequality in poorly conceived interventions which cause significant harm to women.

Like Dry and Leach (2010), I do not advocate throwing out the scientific and medicalised policies and interventions and the stories they construct as they do have value. Others as previously mentioned in this thesis, have suggested tangible ways to address the problems around gender inequality within global health, such as the need for sex-disaggregated data, gender responsive policy and programmes and the empowerment of women. I suggest that while gender responsive policies and programmes are needed, they fail to address fundamental issues around power imbalances in global health and neoliberal ideologies which ultimately drive the exacerbation of gender inequality in global health. Further, as I have argued, agencies that comprise the global health system uncritically adopt empowerment and the feminisation of responsibility and this contributes significantly to the feminisation of health. As long as global health and its powerful actors see women as resources in the prevention, management and containment of diseases such as Ebola, Zika and HIV/AIDS the exacerbation of gender inequality will continue. Finally, this research hopes to contribute to the ongoing conversations about gender inequality, particularly within the context of global health and challenge the ways in which women and their gendered roles are used as resources in the prevention, management and containment of disease.

## APPENDIX A: LIST OF CARE AND WHO POLICY DOCUMENTS REFERRED TO

Total number of policy documents collected for this thesis 63

CARE (2010). Fighting poverty is the key issue in fighting HIV AIDS. Retrieved from

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