Abstract

Considering the current Ebola outbreak in the DRC, analysis of previous outbreaks is potent to learn ‘best practices’. This dissertation utilises a qualitative methodology of secondary literature and key-informant interviews with thematic analysis to understand,

CONTENTS

List of Appendices

List of Abbreviations

CCCs	Community-Care Centres
DFID	Department for International Development (UK)
ERAP	Ebola Response Anthropology Platform
ETCs	Ebola Treatment Centres
INGOs	International Non-governmental Organisations
IOs	International Organisations
PHEIC	Public Health Emergency of InterT/F1 11.04 Tf1 0 0 1 135.00000887/000887

Organisations c A00012l/000 1 39sl( )] TJETQq0.000008871 0 595.32 841.92 reW*nBT/F2000008871 0 595.32 8417q492.3880.0000

1.0 Introduction

Ebola is an infectious disease that gained global attention during the 2013-2016 outbreak in West Africa. This outbreak was unprecedented in terms of location, scale and speed (Coltart et al., 2017). Previous outbreaks had been limited to equatorial Africa, had mostly occurred in remote areas, were quickly contained and never exceeded 425 cases (Kaner and Schaak, 2016; Coltart et al., 2017; CDC, 2019). Comparatively, the West African outbreak spanned rural and urban areas with 28,616 cases across three countries[1] – Guinea, Liberia, Sierra Leone – took three years to contain and became a Public Health Emergency of International Concern (PHEIC) (Coltart et al., 2017). Sierra Leone, which this paper focuses on, was significantly affected, with the highest case-rate in real terms and as a percentage of the population (CDC, 2019).

In Sierra Leone, the PHEIC declaration became the catalyst for a significant and unprecedented international response, whereby international organisations (IOs) (including INGOs, multi-lateral organisations and international governments) provided support for the national response. This dissertation focuses on this international response. Whilst most of these IOs worked within the national response framework, it is possible to distinguish between the ‘international’ and ‘national’ response because IOs had particular influence and in some cases independence to direct and implement interventions. As will be discussed, the implications of international res/F2 Gnrla5(i)-4(ona)9(l)-4(r)7(e)9(s

2.0 Literature Review and Theoretical Framework

However, the focus on Guinea and Liberia limits the application of findings elsewhere because it is unlikely that the barriers and facilitators are the same across these countries. This is because they have different historical and political-economic contexts and potently the responses were different in each country with differing dynamics to local communities. For example, Wilkinson

DV410

McLeroy et al.'s (1988) conceptual framework – building on the earlier work of Brofenbrenner (1979) – has been adopted in this study because it serves to direct socio-ecological attention to both behaviour and its individual and environmental determinants. For example, McLeroy et al. (1988) divide environmental health behaviour influences into five levels to reflect micro, meso and macro interactions (figure 1).

Figure 1: McLeroy et al. socio-ecological framework of multilevel influences on health behaviour

2.2.2. Framing of TSB within Social Practice Theory

TSB takes place in a social and cultural milieu reflecting an interplay between habit, automatic, functional and reciprocal responses to the immediate and wider environments, conscious choice and calculation (Kelly and Barker 2016). Therefore, efforts to change behaviour must consider social context and the political, economic and cultural forces that act directly on people. TSB is therefore framed in this study as a mutually and socially constructed ecological type of health behaviour that is underpinned by a socia

DV410

3.1.4 Inclusion and exclusion criteria

All met the inclusion criteria of: being in Sierra Leone for more than eight weeks during the outbreak; actively worked on the Ebola response whilst primarily employed or contracted by an international (non-Sierra Leonean) organisation; and having knowledge of some element of the overall response mechanisms or coordination, as opposed to just clinical experience. The inclusion of international organisation employees was based on the belief that international responders would be best placed to reveal the methods of international organisations to address barriers to TSB. Exclusion criteria included lack of English fluency.

All key-informants fitting the inclusion criteria were c(q0.0.000008871 0 595.32 841.92 reW*nBT/F1 11.04 Tf1 0 0 1 9

All

Confidentiality was assured for all key-informants during the data collection and analytical stages. All information was securely stored on a password-protected computer in compliance with the Data Protection Act (2018). All names of key-informants and the organisations they worked for were anonymised, and cumulative identifiable features removed, as the research finding

4.0 Findings

Widespread mistrust of official responders contributed to reduced TSB because people feared that responders would harm them (UNDP, 2014). For example, quarantine was resisted when rumours emerged that the food provided was intended to kill recipients (Wigmore, 2015).

Other rumours articulated the outbreak as fake (Frankfurter, 2014), a government conspiracy to depopulate opposition areas in a run-up to an important census (Feuer, 2014; Frankfurter, 2014; ACAPS 2015; Wilkinson and Fairhead, 2017); or an international conspiracy for international workers to undertake cannibalism and sell organs (Fofana, 2014; ACAPS 2016; Quick and Fryer, 2018). The implications of these rumours are highlighted by key-informant three:

> *s not a naturally caused [disease] outbreak The outbreak started in an opposition held area, the outbreak started just when they were going to do a census to determine the next election. You know and the outbreak happened in an area where the US military had their own infectious disease research institute. And so they did not believe the messages as they were being told to them by the*

Mistrust, rumours and fear appeared to therefore threaten TSB at both an intra- and inter-personal levels because they exposed ideological differences between their culture and the dominant biomedical narrative.

4.3 Theme Two: Messaging (barrier and facilitator)

'Messaging' in this context refers to the public provision of information regarding what to do and not do during the Ebola outbreak to minimise transmission. The theme of messaging as both a barrier and facilitator of TSB reoccurred across key-informant interviews and literature analysis.

Messaging as a barrier

Messaging in the early outbreak was widely considered to be both ineffective and a barrier to TSB (GOAL, 2014; ACAPS, 2015; Wilkinson, 2016). For example, key-informant two:

> *will die of Ebola and*

DV410

The ERAP was particularly praised in evaluative literature, for example:

> *helped] to shape policy in Sierra Leone. It provided rapid-response advice to government, international agencies and NGOs on issues relating to burials, movement, and communications, enabling these to be more socially and culturally appropriate and therefore effectiv (IDS, 2016).*

A perspective also taken up by key-informant two:

> *anthropologists] did quite a good job in helping to rethink, from quite small things, like the colour of body bags and to what extent when the body bags were black they looked like bin liners and the perception around that with black and death...And shifting burials so that actually you could*

However, whilst the literature perceived anthropologists as overwhelmingly helpful, key-participants also recognised their limitations, for example key-informant two:

> *Understanding TSB barriers] came along when the anthropology platform was set up and they started asking these question but a lot of it came quite late a*
> *sometimes someone would do a study and it would sit with DFID, or it would sit with UNICEF, but to the extent that it made its way to someone like me on the frontline of the health facility, actually deciding what to call things and where to put the entrances it did*

Key-informants argued that anthropologists were more effective when (Key-informant three) i.e. integrated into the official response mechanisms which enhanced timely dissemination and implementation of results compared with those advising from outside the country. For example, ERAP's findings, perceived to be London-based, took time to reach decision-makers and front-line staff in Sierra Leone.

4.6 Theme Five: Addressing livelihood concerns

International organisations working on the Ebola response in Sierra Leone were at the forefront of campaigns to mitigate the impact of the biomedical Ebola interventions on livelihoods of Sierra Leoneans (DEC Emergency Response Program, 2016; Participant 2). This was important because many people wanted to seek treatment, but socio-economic practicalities prevented them (Wilkinson and Fairhead, 2017). As participant one articulates:

> *a healthca , in order to persuade you to come in and get we have to provide support to*

5.1 Theme One: Mistrust, Fear and Rumours

This theme highlighted that fear fuelled by mistrust of responders and rumours acted as a barrier that prevented people from seeking treatment during the Ebola outbreak.

Mistrust of responders fuelled rumours that Ebola was not real, which at the intra-personal level of the socio-ecological framework may have reduced self-efficacy and perceived susceptibility to and severity of Ebola, which are important influencers of intra-personal behaviour (USDHHS, 2005). Thus, by perceiving responders negatively – that responders would harm them – this deterred the perceived benefits of seeking treatment, so people were initially less likely to do so. Other authors

5.2 Theme Two: Messaging

This theme highlighted that the response's messaging was both a barrier and facilitator to TSB.

Messaging initially focused on the simple provision of information and was based on the false belief that humans are rational entities whose health behaviour is purely driven by rational cognitions (Kelly and Barker, 2016). However, the socio-ecological and social practice frameworks highlight there are multiple influences of health behaviour and that for behaviour to change, the message must have personal meaning, the people themselves have to feel competent to uphold the desired behaviour and that they have available resources to do so. Initial messaging failed to incorporate these, and therefore became a barrier. Gillespie et al. (2016), DuBois et al. (2015) and WHO (2015a) concur that messaging contributed to treatment avoidance through the belief that treatment would not be helpful. Through a focus-group study with Sierra Leoneans, Carter et al. (2017b) also found that messages of 'incurability' deterred TSB. This was not a problem unique to Sierra Leone. Ling et al. (2017) found similar problematic and ineffective early messaging in Liberia.

Theme two also indicates how the response improved messaging over time. For example, by using effective dynamic communications including radio talk shows with phone-ins and radio dramas (BBC Media Action, 2019). These methods actively engaged people and allowed them to feel listened to, as well as reducing their fears and counteracting rumours using trusted community influencers who conveyed treatment-seeking promoting messages in a way that would be more readily accepted. Providing action-based messaging, focusing on things people could do that combined cultural norms with biomedical safety measures, also promoted TSB by increasing self-efficacy and decreasing treatment fears (ACAPS, 2016).

From a socio-ecological lens, these TSB interventions target both intrapersonal and interpersonal levels – the former through knowledge, attitudinal and belief influence and the latter by initiating interpersonal positive discussions on TSB that could disseminate treatment-seeking advice through social networks. Latkin and Knowlton (2015) highlight the importance of social network support in promoting health behaviour, suggesting that this strategy had the potential to be effective.

Key

Lastly, the recent news of a successful Ebola cure is a positive advancement and will dramatically reduce the suffering caused. However, with the news of this biomedically grounded intervention it is important to emphasise that this cure is not sufficient to end Ebola outbreaks alone. As Dr Johnson (2019) an influential responder during the Sierra Leonean Ebola outbreak, articulated:

As this dissertation has emphasised, any response that would like to increase TSB needs to address multiple levels of health behaviour. Biomedical interventions are insufficient. Instead, ‘compromises’ must be made to make necessary interventions socially acceptable and behaviour change possible, which, as this dissertation has indicated can be addressed through dynamic messaging, community engagement and livelihood support.

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DV410

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Appendix 2: Interview Information Guide

Interview Information Guide

Addressing Barriers to Treatment-Seeking Behaviour During Ebola in Sierra Leone and The International Response

What were the barriers that prevented Ebola-infected people seeking healthcare services during the Ebola outbreak in Sierra Leone? How did the international intervention address such structural barriers?

Name of researcher: Natasha Glendening (MSc African Development student in the Department of International Development, London School of Economics and Political Science)

Information for participants:

Thank you for considering participating in this research study which will take place between 10th July 2019 and 4th August 2019. This information guide outlines the purpose of this research study and a description of your involvement and rights as a participant if you agree to participate.

What is the research study?

This research study will contribute to my master's dissertation, a 10,000-word research project that I am doing to fulfil the requirements for my master's in African Development at the London School of Economics and Political Science. I have decided to focus this project on the international response to Ebola in Sierra Leone.

What is the research study about?

This research project explores the international response to the Ebola outbreak in Sierra Leone and how the response addressed barriers that prevented Ebola infected people from seeking and accessing healthcare during the outbreak in 2014-2015. I am particularly interested in establishing how international responders identified barriers that prevented people seeking healthcare services and what methods were used to improve the percentage of infected people accessing healthcare services.

Do I have to take part?

It is your decision whether or not you take part in this research study. You do not have to participate if you do not want to. If you do decide to participate, I will ask you to sign a consent form which you can sign and return to me in advance of the interview or at the meeting. If the interview takes place over the phone or Skype video call, you can sign the form digitally and email it back.

What will my involvement be as a participant?

You will be asked to participate in an interview about your experience of the Ebola outbreak in Sierra Leone (2014-2015). The focus of the interview will be on how international responders addressed the barriers that infected people faced in accessing healthcare services.

The interview should take around 45-60 minutes and can take place in several ways, depending on what is convenient to you: either in person in London, over the phone, or through Skype video call. The interview will be audio-recorded.

I am looking to complete these interviews before the 4th August 2019, but the specific time and date of the interview can be set at any convenient time for you.

How do I withdraw from this research study?

You can withdraw from the study at any point without a reason, via email or during the interview itself. If any questions during the interview make you feel uncomfortable, or you do not wish to answer for any reason, you are not obligated to do so. Withdrawing from the study will have no effect on you. If you withdraw from the study, your information you have provided so far will not be retained, unless you consent to it.

What will my information be used for?

I will use your answers from the interview as part of a 10,000-word dissertation I am writing as part of my master's degree in African Development. The dissertation will also be informed by a literature review. All answers will be anonymised, and your name will not be attributed to your answers in the final dissertation.

Will my data be kept confidential?

Appendix 3: Consent Form

Consent Form

Research Title: Barriers to Treatment-Seeking Behaviour During Ebola in Sierra Leone and The International Response

Research Questions: What were the barriers that prevented Ebola-infected people seeking healthcare services during the Ebola outbreak in Sierra Leone? How did the international intervention address such barriers?

Researcher Name: Natasha Glendening

Please note that participation in this research study is voluntary and you can withdraw at any point.

I have read and understand the study information dated (08/07/19) or it has been read to me.	YES/NO
I have been able to ask questions about the study and my questions and have been answered to my satisfaction.	YES/NO
I consent voluntarily to participate in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.	YES/NO
I agree to the interview being audio recorded. I understand that the interview will take place over Skype/Video Call but video recording will not take place	YES/NO
I understand that the information I provide will be used for a master's dissertation and that all information I provide will be anonymised.	YES/NO
I agree that my information can be quoted in research outputs.	YES/NO
I understand that any personal information that can identify me – such as my name or addresses – will be kept confidential and will not be shared with anyone else beyond the researcher	YES/NO

Participant name: _____

Appendix 4: Interview Schedule

What did you do during the Ebola outbreak in Sierra Leone?

When were you in Sierra Leone?

> Where were you located?
> What areas did you work in?

What were the biggest challenges for the international response?

From your experience, why do you think people refused treatment for Ebola or to be engaged in the Ebola response in general?

> Was this different in different places? Or over time?

How did international responders identify the reasons why people did not want to seek treatment for Ebola?

> Did they identify these reasons accurately?

What did international responders do to improve access to Ebola treatment and encourage people to change behaviour practices and seek healthcare?

How did international responders work with local people in dealing with Ebola?

> Was working with local people a priority?
> Were international responders respectful of local cultures?
> Were local people engaged in discussions or did international responders use force in seeking compliance?

How did methods to improve treatment-seeking behaviour change over the course of the Ebola outbreak?

> When did they change?

Was the response too Ebola too focused on biomedical models of disease and security instead of prioritising socially acceptable forms of containing Ebola?

> Did this change over time?

Do you think that the use of anthropologists to liase with communities made a difference? (was this a frequent practice)

Do you know of the Ebola Response Anthropology Platform? Do you think that the work written, uploaded and shared in real-time made a difference to how the international response to Ebola communicated with local people?

Appendix 5: Braun and Clarke's (2006) Framework for Thematic Analysis

Phase	Phase	Description of the process
1.	**Familiarisation with data**	Transcribing (verbatim), reading and re-reading data sets Noting down initial themes
2.	**Generating initial codes**	Systematically coding interesting features in the entire data set Collating data relevant to each code
	Searching for themes	Collating codes into potential themes Gathering all data relevant to each potential theme
4.	**Reviewing the themes**	Level (1): Checking that the themes work in relation to the coded extracts Level (2): Checking that the themes work in relation to the entire data set Generating an analytical "theme map"

DV410