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Addressing barriers to treatment-seeking behaviour during the Ebola outbreak in Sierra Leone: An International Response Perspective.

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Addressing barriers to treatment-seeking behaviour
during the Ebola outbreak in Sierra Leone (2014-2016):
An International Response Perspective

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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, from the perspective of the international response, what the barriers to treatment-seeking behaviour during the Ebola outbreak in Sierra Leone (2014-2016) were, and how the international response addressed these barriers. Given that health behaviour plays an important role in Ebola outbreaks, this dissertation also adopts a socio-ecological and social practice lens to help fill a gap in the current literature.

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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 International Concern
SMAC	Social Mobilisation Action Consortium
TA	Thematic Analysis
TSB	Treatment-Seeking Behaviour
WHO	World Health Organisation

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 countries¹ – 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 responders implementing interventions was also different from that of national personnel.

Furthermore, whilst the international response in Sierra Leone covered many aspects of the outbreak, an important part of the response was health behaviour, particularly surrounding the adoption of health promoting behaviours and avoidance of high-risk ones. Indeed, many argue that the Ebola outbreak in Sierra Leone ended due to mass-behaviour change (Richards, 2016; Hayashi and Eisenberg, 2017). Treatment-seeking behaviour (TSB) is one aspect of health behaviour that contributed to ending Ebola transmission. This is particularly important given the recent discovery of a successful Ebola vaccine (Guardian, 2019) as eradication will only be possible if people willingly seek this treatment (EBOVAC Projects, 2019).

This dissertation consequently seeks to understand, from the perspectives of international responders:

- ***What were the barriers to treatment-seeking behaviour (TSB) during the Ebola outbreak in Sierra Leone?***
- ***How did the international response address such barriers?***

¹ Less than 1% of cases were reported elsewhere.

Whilst this outbreak ended three years ago, it is still important to analyse. Given the ongoing Ebola outbreak in the DRC, currently the second largest ever and also a PHEIC (MSF, 2019), lessons from the largest Ebola outbreak are fundamental to avoid previous mistakes and to ensure increased effectiveness of future interventions. It is particularly important to understand the barriers and facilitators to behaviour change, particularly TSB and the Ebola response methods to promote it, to infer best-practices for current and future outbreaks. The lessons from the international response are also pertinent, because future outbreaks are likely to involve international responders again.

Despite the importance of understanding barriers to TSB during outbreaks such as in Sierra Leone, it has not received the attention it requires in current research. Whilst it is touched upon, TSB specifically is not usually the focal point of the research and details of the response methods are often limited to grey-literature. This paper consequently draws on existing literature, in relation to TSB barriers and how these were addressed by international organisations in Sierra Leone, whilst also using new interviews with key-informant's working with international organisations in Sierra Leone, to understand this.

This dissertation is outlined as follows: chapter two reviews the literature concerning TSB during Ebola outbreaks and the international response to the West Africa outbreak, whilst also explaining key concepts in the research questions; chapter two also outlines the theoretical framework; section three details the methodology used; section four details the key themes found, section five is the discussion of the themes and section six concludes.

2.0 Literature Review and Theoretical Framework

This chapter seeks to discuss what is already known about the West Africa Ebola outbreak, specifically concerning Sierra Leone and TSB and the response to the outbreak overall. However, this remains brief given the secondary analysis of literature within the research design. The research questions and objectives of this dissertation are outlined, alongside the theoretical framework.

2.1 Literature Review

The West African Ebola outbreak has become a growing research topic spanning multiple disciplines. A significant focus within the social science literature pertains to explaining why the outbreak grew to unprecedented levels, often utilising a ‘structural violence’ or ‘political economy’ framework (Benator, 2015; Benton and Dionne, 2015; Sanders et al., 2015; Obeng-Odoom and Bockarie, 2018; Sirleaf, 2018). However, this review focuses mainly on TSB and the outbreak response instead.

2.1.1 Treatment-Seeking Behaviour (TSB)

‘Treatment-seeking behaviour’ in the context of the West African Ebola outbreak is defined as:

“any action taken by an individual or community once a person is believed to have contracted Ebola” (Carter et al., 2017a:32).

This includes going for testing or treatment at official healthcare providers (i.e. Community-Care Centres (CCCs), hospitals or Ebola Treatment Centres (ETCs); reporting others as suspected cases; or calling 117 (Ebola hotline) (Carter et al., 2017a).

Whilst there was no cure or licensed treatment² to manage Ebola during the 2013-2016 outbreak, basic interventions (‘treatments’) such as rehydration and symptomatic treatment have proven to increase survival rates (Briand et al., 2014; CDC, 2017; Bourrier, 2019; Malvy et al., 2019; WHO, 2019). Evidence also suggests that survival rates were higher in official healthcare settings, although this is disputed (Malvy et al., 2019). Seeking treatment at official healthcare providers also helped to reduce transmission through isolation (WHO Ebola Response Team, 2016). Consequently, TSB played an important role in ending the outbreak (Carter et al., 2017a).

² Vaccines were first trialled across West Africa in 2015 and in August 2019 successful trials were completed in the DRC (Guardian, 2019).

TSB is part of a broad literature on behaviour change, particularly in contexts where seeking treatment is not necessarily an immediate reaction to becoming symptomatic with any disease, including Sierra Leone³ (Wurie et al., 2012; Ministry of Health and Sanitation, 2017; Treacy et al., 2018).

Literature specifically focusing on TSB, its barriers and facilitators, in an Ebola context is lacking. However, common qualitative methodologies amongst existing literature focusing on TSB include the use of focus groups and interviews limited to single communities (Abramowitz et al., 2015; Allen et al., 2015; Carter et al., 2017a; Kuehne et al., 2016; Gautier et al., 2017; Kodish et al., 2018). These methods limit the application of findings across different communities which could be useful to analyse interventions. These methods are usually implemented with a view to understanding TSB from the perspective of local people, but some also seek perspectives of responders as well (e.g. Allen et al., 2015). Whilst the perspectives of local people are key, as they are the ones experiencing the barriers to TSB, the inclusion and understanding of responders' perceptions is also important, because it is these perceptions that are likely to guide their actions within the response.

However, most of this literature focuses on TSB intention theoretically as opposed to understanding TSB barriers or facilitators; this often ignores the 'gap' between behavioural intentions and actual behaviour (Sheeran, 2002; Sniehotta and Schwarzer, 2005; Sheeran and Webb, 2016). When TSB barriers or facilitators are mentioned, few explicitly focus on Sierra Leone (e.g. Yamanis et al., 2016; Carter et al., 2017a; 2017b), with some pertaining to Guinea-Bissau (e.g. Gamma et al., 2017) and a majority on Guinea and Liberia (e.g. Allen et al., 2015). Discussion of TSB barriers in Sierra Leone is often the prevue of grey-literature instead (e.g. Grant, 2014).

Key themes regarding barriers include: culture; inaccessibility of services; mistrust of governments and international responders; fear and rumours (e.g. Shultz et al., 2016; Kinsman et al., 2017). Rumours have been particularly highlighted in the media and peer-review work as reasons why people avoided official healthcare or withdrew themselves or family members from treatment facilities (Fofana, 2014; Mark, 2014; Martin, 2019).

³ Reasons include: lack of accessibility and affordability, and bad experiences with medical personnel.

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 potentially the responses were different in each country with differing dynamics to local communities. For example, Wilkinson and Fairhead (2017) highlights these differences by arguing that the differing political environments in Liberia and Sierra Leone help explain the difference in levels of resistance towards international responders. Other studies that focused on TSB included quantitative methods, but the focus was limited to predicting the temporal change in treatment-seeking behaviour (e.g. Funk et al., 2017).

2.1.2 International Response

The international community has been criticised for its slow response to the West African outbreak particularly when it was clear that national governments did not have sufficient capacity to contain Ebola and despite repeated calls from MSF (2015) that the outbreak had grown uncontrollable (IDC, 2014; Roemer-Mahler and Rushton, 2015; Rull et al., 2015; McCarthy, 2016; Hoffman and Silverberg, 2018). Therefore, a key theme in the response literature is discussion of why the response was so slow, including factors such as recent WHO reforms (Wilkinson and Leach, 2014; Kamradt-Scott, 2015) and perceptions of Ebola as an ‘African problem’ among global actors (Nunnes, 2015). The latter feeds into the concept of the ‘outbreak narrative’ whereby international actors are only mobilised once a disease spreads internationally and threatens the ‘Global North’ (Leach, 2008; Wald, 2008; Wilkinson and Leach, 2014).

Another theme across the literature is an emphasis on the barriers to response success, such as community resistance, particularly towards international responders and continued cultural practices like burials that increased Ebola’s spread (Fairhead, 2014; Manguvo and Mafuvadze, 2015; Tiffany et al., 2017; Gray et al., 2018; WHO 2015a).

Whilst peer-review literature does highlight and critique what the international response did and did not do regarding ending Ebola in Sierra Leone, and specifically regarding behaviour change, the methods the response used is mostly detailed in the grey literature of international organisations involved in the response (e.g. Wilkinson, 2016). Key themes across this literature regarding the response’s methods to promote behaviour change (of which TSB was a part of) generally include: use of messaging (e.g. radio, billboards, loud speakers) and social mobilisation strategies (involvement of community leaders, discussions, ambulance demonstrations) (e.g. Gillespie et al., 2016; Kinsman et al., 2017; Ross et al., 2017).

2.1.3 Local responses

The response to Ebola, including behavioural change, has previously been analysed from local community responses across West Africa (Polygeia, 2016), specifically in Liberia (Sharma et al., 2014; Abramowitz et al., 2015) and Sierra Leone (Richards et al., 2015; Richards, 2016; Polgeia, 2016; Parker and Allen, 2018; Parker et al., 2019). Common qualitative methodologies used are interviews or focus-groups with a singular local community, to highlight the perspectives of local people. This builds upon the work of Hewlett and Hewlett (2008) who analysed local perceptions and behaviour change responses during previous Ebola outbreaks.

The main argument in such studies is that local communities were more effective at ending the outbreak because they could tailor interventions to local dynamics and legitimacy (Parker et al., 2019). This is despite lack of support at international and national response levels, that at times actively deterred local initiatives (Southall et al., 2017; Walsh and Johnson, 2018). Indeed, Parker et al. (2019) are quite critical of the international response in comparison, for their top-down, culturally insensitive and illegitimate approaches to Ebola containment.

However, there is also some overlap between the dynamics of international and local responses, given that community engagement was a key response mechanism for the international response, including facilitating local community action, albeit in a top-down way (Polygeia, 2016). Nonetheless, a key argument in this strand of literature is that in many cases behaviour-change initiatives originated locally. For example, Richards (2016) emphasises the initially locally-originating role of Chiefs in enacting local by-laws and initiatives to enforce behaviour change in local communities, through fines for people who did not seek official treatment when becoming symptomatic (Wilkinson and Fairhead, 2017).

2.2. Theoretical Frameworks

2.2.1 Socio-ecological context of health

This study conceptualises health within a socio-ecological context, emphasising the interaction and interdependence of factors across all levels of health concern, including people's interactions with their socio-cultural and physical environment. Key premises underpinning this perspective are that health behaviour both affects and is affected by 'multiple levels of influence' and that individual behaviour shapes and is shaped by reciprocal causation (USDHHS, 2005).

McLeroy et al.'s (1988) conceptual framework – building on the earlier work of Bronfenbrenner (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).

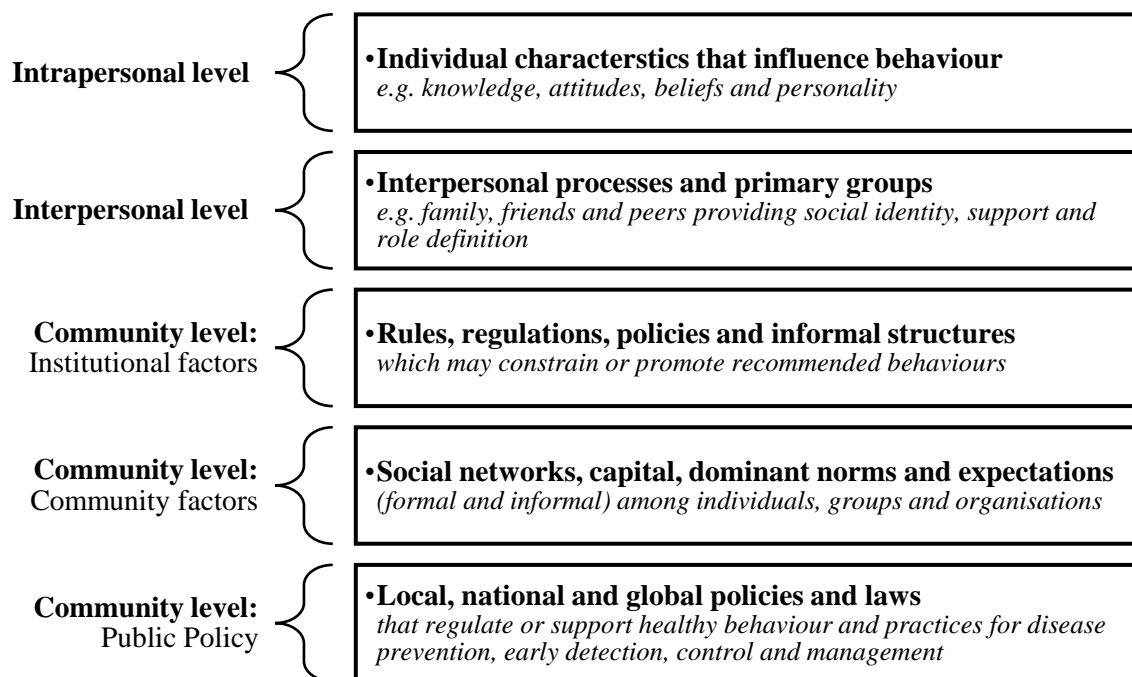


Figure 1: McLeroy et al.'s (1988) socio-ecological framework of multilevel influences on health behaviour

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 social practice ontology to frame how health behaviours such as TSB can be understood. Not in isolation from other individuals and as a single behaviour, but rather as a heterogeneous set of activities and barriers that are embedded in the complexity and practicalities of the everyday lives of those involved.

This theoretical position departs from much previous health behaviour research by responding to the criticisms of cognitive-behavioural explanations that adopts a narrow focus of health behaviours as a series of purely rationalised individual behaviours which reduces people to a sequence of individual conscious decisions, largely devoid of social context (e.g. Frohlich et al., 2001; Maller 2015; Kelly and Barker 2016). Instead, Social Practice Theory conceptualises health behaviour, as relations between interacting individuals, groups and institutions that exist beyond what individuals themselves do (Kelly and Barker, 2016). Consequently, Maller (2015) argues that social practice theories have more to offer than has perhaps currently been capitalised upon.

Accordingly, Shove et al.'s (2012) social practice model suggests that health behaviour ("practices") are combinations of three interconnected elements, namely: meanings, competencies and materials. Health behaviour is thus operationalized as the contextual bringing together of these elements.

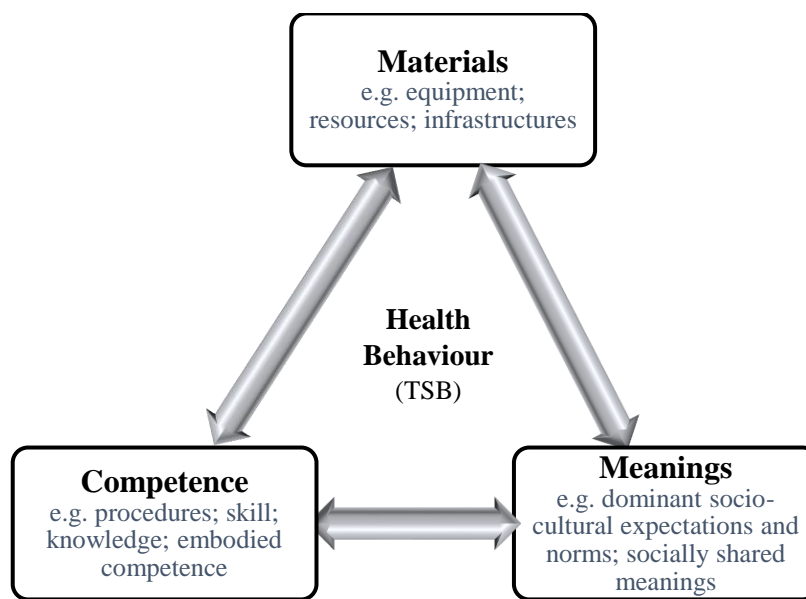


Figure 2: Shove et al.'s (2012) social practice model

This dissertation combines this complementary socio-ecological and social practice perspective to uniquely analyse the barriers to TSB and the international response' attempts to address them. It is used to frame both data collection and analysis within this dissertation. Such theoretical approaches can also arguably help better understand these behaviours whilst also avoiding the common overemphasis on individuals and the resultant individual responsibility paradigm that can often emerge.

2.3 Research Question

There remain gaps in the current knowledge and analysis of TSB in Sierra Leone during the outbreak, particularly from the perspectives of international responders. These gaps include: research going beyond descriptions of temporal trends in TSB and theoretical intentions; research focusing on Sierra Leone; and academic literature focusing on international response methods.

This dissertation, through a socio-ecological and social practice lens, seeks to understand two things from the perspectives of international responders:

- *What were the barriers to treatment-seeking behaviour during the Ebola outbreak in Sierra Leone?*
- *How did the international response address such barriers?*

These questions focus on the processes of the response in addressing barriers to TSB, they do not seek to draw evaluative claims of the success or failure of these processes. Instead they explain what the barriers to TSB were and how the international response addressed them contextually.

2.3.1 Further Definitions

The '*international response*' in this context refers to non-Sierra Leonean organisations and actors (including multilateral organisations, international non-governmental organisations (INGOs) and governments) who provided resources (human and physical), advice and contributed to the direction and implementation of strategies to end the Sierra Leonean Ebola outbreak. This excludes organisations whose activities exclusively focused on strategies to prepare for or respond to Ebola outside of Sierra Leone.

'International responders' refers to people who were primarily employed or contracted by international organisations, who worked on the response to end the Sierra Leonean Ebola outbreak.

The focus on the international response is not intended to neglect or diminish the role of local or national responses, rather this chosen focus is an acknowledgement that analysis of local Ebola responses is burgeoning. It is also a recognition that the international response is important to analyse because international organisations are very likely to be part of future outbreaks. Thus, lessons from previous outbreaks specifically pertaining to the actions of international responders are pertinent to learn.

3.0 Methodology

This chapter examines the methodological basis of this two-part qualitative study together with the thematic analysis research method and design adopted. This dissertation adopted a complimentary methodological approach, utilising secondary data analysis of the extant literature concerning the international community's response to the Ebola outbreak in Sierra Leone and their methods to promote behaviour change and address barriers to TSB. It adopts an inductive semantic thematic analysis of a purposefully and snow-ball selected sample of key-informant interviews.

A qualitative approach was deemed congruent with the research question. Qualitative research focuses on the "way people make sense of their experiences and the world in which they live" (Holloway and Wheeler 2010:3). It is an inductive approach for understanding the meaning individuals and groups themselves ascribe to their social worlds. Based on an interpretative paradigm (Holloway and Wheeler 2010), social reality is ontologically assumed to be experienced by people who each interpret events differently, leading to multiple perspectives and subjective meanings. This relativist and constructivist ontology acknowledge that more than one "truth" exists and thus interpretative research becomes less concerned with finding *the* truth and more with "opening up of possibilities" since understanding is considered to be embedded in unique interactions and personal interpretations of the world (Houghton et al., 2012).

3.1. Data Collection

3.1.1. Literature Review (Secondary data analysis)

The re-use and re-contextualising of extant data is an increasingly recognised method in social science disciplines (Irwin and Winterton 2011) aiming to supplement new primary data and prioritise concepts present in original data but that were not necessarily the original analytical focus. A literature review was therefore undertaken as part of the secondary data analysis to compliment and structure the key-informant interviews and thus provide more depth when answering the research question. When key-informants raised new issues, not previously found in the literature collation, or referenced specific organisational grey literature, I returned to the literature. In this sense the process between the two methodologies was iterative. Having a two-pronged methodology also allowed analysis of potential differences in the focus and issues raised between the available literature (mostly from the organisational level) and key-informant interviews (the individual level).

Literature selected was mainly ‘grey literature’ produced by international organisations involved in the response. Such literature often detailed specific organisational responses to Ebola and their containment methods. Peer-reviewed literature was also collected when it referred to specific aspects of the response and behaviour change. Peer-review literature has not to-date explicitly focused on this research question but rather the barriers to the containment and the response overall. However, this literature type still provided useful exploratory and analytical evidence by providing evidence of treatment-seeking behavioural strategies and interventions. Primacy was also given to autobiographical accounts by responders in other print literature..

3.1.2 Search strategy

The search terms used, together with the databases searched are listed in appendix 1.

3.1.3. Sampling (Key-Informant Interviews)

In-depth semi-structured interviews were undertaken with seven key-informants recruited utilising an online search on LinkedIn. A mix of purposive sampling for the six-initial key-informants and snowball sampling for the seventh was utilised. Purposive sampling was chosen to select informants who “best” illustrated features of the phenomenon being studied and for whom the research question had significance (Silverman, 2005). Snowball sampling was a complementary selection method used because of its benefits in increasing sample size for hard-to-reach populations (Atkinson and Flint, 2003). To limit problems with this sampling method, key-informant criteria was relayed to initial informants who recommended other potential informants to ensure robustness of the study.

I was not aiming to achieve a representative sample in terms of probability or population, but rather to select key-informants to best illuminate the research question and develop a rigorous interpretation of the data. My sample size was therefore relatively small and determined by the significant amount of time required to collect, transcribe and analyse the interviews (Cormack, 2000) while also needing to consider attrition risks and sufficient data sources to enable saturation, whereby no new information was discovered (Silverman, 2005).

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 contacted via email inviting participation in the study. Additionally, an information document (appendix 2) including details of the study including purpose; expectations of the key-informants; practical and ethical consideration; a written consent form (appendix 3); and my contact details were also included. This strategy was chosen due to the global dispersion of informants.

3.1.5 Key-Informant characteristics

Key-informants worked in diverse areas of the response across different periods of the Sierra Leone epidemic (Table 1). Whilst this was not an intentional selection criterion, this enabled temporal reflection of the response during thematic analysis.

Participant Number	Role	Time Period in Sierra Leone
Key-Informant 1	Humanitarian Advisor	July 2015–December 2015
Key-Informant 2	Health Advisor (Behaviour Change)	August 2014–February 2015
Key-Informant 3	Public Health Specialist	Pre-Outbreak–August 2015
Key-Informant 4	Humanitarian Advisor	December 2014–May 2015
Key-Informant 5	Logistician	June 2015–December 2015
Key-Informant 6	Communications	Pre-Outbreak–Post-Outbreak
Key-Informant 7	Gender Advisor	November 2014–Post-Outbreak

Table 1: Key-Informant Characteristics

3.1.6 Interviews and transcription

Interviews were conducted via Skype due to the internationally dispersed nature of the sample. Each interview was recorded and transcribed verbatim by myself at the semantic level to enable immersion in the data (Willig, 2013) and reflect the conceptual understanding of communication as more than the transfer of spoken words to also include the transfer of “important” emotions and shared meanings (Hargie and Dickson, 2004).

A semi-structured interview style was employed allowing key-informants to explain their own experiences in their own words and allowing me the opportunity to expand on interesting pathways throughout the interview. An interview schedule was developed prior to data collection (appendix 4). Smith and Osborn (2003) propose that this pre-planning is essential for data collection, particularly to anticipate and address potentially sensitive questions prior to informant involvement. The schedule guided the interview but did not dictate its course, as questions were adapted in light of participant’s previous answers to explore areas of significance. This was important to enable an iterative and inductive inquiry as opposed to researcher imposed. Interview lengths of 45-60 minutes reflected Walker’s (2011) ideas of ideal length for semi-structured interviews which balances potential fatigue with the need for rich data.

Interviews were conducted three years after Sierra Leone’s Ebola outbreak. This time-lapse enabled discovery of key-informants reflective, tacit insights about their experiences which Polanyi (1966) argues are not always explicit during the event itself.

3.1.7 Ethical issues

As this study involves human subjects, ethical approval was sought following the institutional checklist process, prior to requesting research participation. Throughout the study I adhered to the university Research Ethics Code of Practice (LSE, 2019). Meaningful informed consent was collected from each key-informant, in the form of a signed consent form. Each key-informant was also advised that if they wished to withdraw from the study, either before or after their interviews, this request would be respected without explanation, and data collected would be deleted. No key-informants withdrew however.

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 findings may have the potential to harm the organisations and personnel.

3.2. Data Analysis

Following data collection, the data was coded thematically. Thematic analysis (TA) is a systematic and flexible research method for recognising and organising patterns in content and meaning in qualitative data through identifying categories of meaning and culturing these into high-order themes (Willig, 2013). Braun and Clarke (2006:82) propose that a ‘theme’ captures something important about the data that helps address the research question and represents some patterned meaning within and across the data. Similarly, Willig (2013) argues that research questions related to people’s conceptualisations of particular social phenomena are ideally suited to thematic analysis, which added to my method choice.

To structure the data analysis, Braun and Clarke’s (2006) six stage framework was employed (appendix 5). This involved multiple readings of the data to increase familiarity before systematically and manually producing initial codes related to the research question for each data item. The initial themes were then organised and collapsed into broader themes, before refinement to identify the “story” and relevant naming of themes.

3.3 Limitations

This dissertation seeks to contribute to the understandings of the Sierra Leonean Ebola outbreak in a methodologically rigorous way, however some limitations remain. Because this dissertation has focused on one Ebola outbreak, the results are context-dependant, and consequently may have limited generalisability. Similarly, whilst this dissertation focuses on the international responders’ perspectives, other perspectives exist.

There is also potential for result-bias due to the use of grey-literature from responding organisations and key-informants to collect data on the response they were part of, because they may not want to acknowledge any potential problems with their contribution. However, this method was chosen because these data sources were best placed to provide insights into response dynamics, and to understand the research questions considering responder perspectives. Additionally, the findings indicate the key-informants to be particularly self-reflective and self-critical of the response's success and failures.

Purposeful and snow-ball sampling was used to gain access to a 'hidden' and dispersed populations whom were able to provide information-rich data. However, this can also be open to researcher selection-bias (Palinkas et al., 2015). Nonetheless saturation did occur across interviews and literature indicating this was less problematic.

Secondary data analysis has also been criticised because the original research does not always address the contemporary research question directly nor are methods under current researcher control. However, saturation between the interviews and data suggest this was not too problematic. It also suggests that potential problems of recall delay and temporal bias (MacLeod et al., 2018) were not influential.

4.0 Findings

This study seeks to understand the barriers to TSB during the Ebola epidemic in Sierra Leone and how the international response addressed them. Thematic analysis of interview transcripts and secondary literature analysis resulted in one overarching theme “*changing health narratives*” and five major themes.

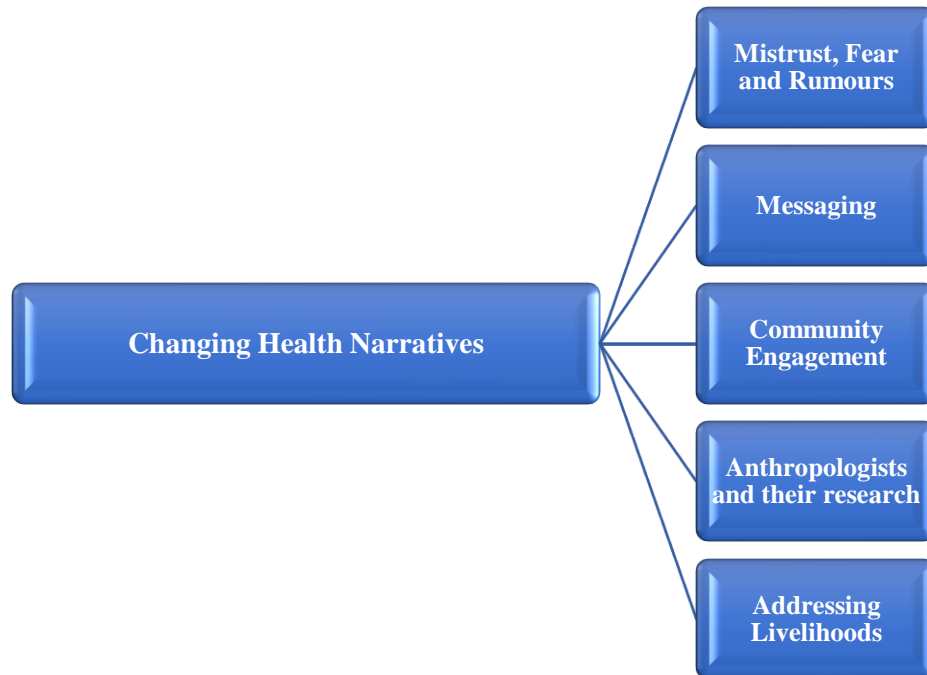


Figure 3: Themes revealed in the data analysis

4.1 Overarching theme: Changing health narratives

This theme permeated all other themes, having a powerful ideological, multi-level and temporal influence on both the identified TSB barriers and responses to these. For example, the early dominant and reified narrative of biomedicine to stop pathogen spread initially appeared to be perceived by responders as the only “*correct*” way to deal with the outbreak, as identified by key-informant four:

“I think there was an overreliance on the biomedical side initially because that was the only way to respond to it, you know it was a medical emergency...you try to contain it medically”.

However, this narrow Western scientific lens silenced and trivialised alternative discourses fuelling fear, rumour and mistrust as well as proving insensitive and oft-antagonistic towards Sierra Leonean cultural and work practices.

ACAPS (2016:39) articulate this insensitive and trivialisation barrier produced by an early biomedical narrative:

At the beginning of the outbreak, humanitarian responders approached the crisis with a medical and technical perspectives and neglected the traditional aspect of the disease and the burials. The response perceived the burials as the simple collection and disposal of bodies, while for the affected population these were linked to heritage, territory and identity...which triggered resentment, resistance and trauma.”

This lack of respect and incorporation of cultural (burial) rites is also highlighted as a TSB barrier by key-informant three:

“It’s almost better to die [without seeking official treatment] and to have a good burial...at home, than to have that [biomedical] experience.”

Narrative silencing and cultural misunderstanding also led to a binary “them and us” form of othering whereby local knowledge was initially perceived as “*bad*” and a diametrically opposed barrier to “*good*” TSB. Consequently, the initial response generally ignored or suppressed local initiatives to combat Ebola (IDS, 2016; Johnson et al. 2016). This alienated many people and contributed to a sense of powerlessness and mistrust, reducing the probability they would seek treatment.

The preoccupation with the ‘science of Ebola’ and biomedical preventative measures (e.g. don’t touch infected people, early symptomatic treatment seeking) relayed through over-simplistic and “expert-led” early messaging was insufficient to ensure behaviour change. This failure to consider the practicalities of TSB had prohibitive barriers for some people (Frankfurter, 2014; Chandler et al., 2015). Thus, while biomedically correct, early messages ignored that people did not trust the messengers (e.g. internationals or the government) and that cognitive influences alone were insufficient to facilitate TSB.

A temporal change in the health narrative reducing the dominance of biomedicine, was noted across the data

*“At the beginning the whole response was virus centric and then it [became] human centric”
(Key-informant five)*

This ideological paradigm shift, as responders increasingly recognised the value *and* limits of biomedicine more critically, led to a more socio-ecological health narrative emerging alongside a biomedical response to TSB. For example:

“When people’s practical and emotional needs were met, rumours and resistance diminished. Taking rumours seriously can explain people’s anxieties concerning health facilities, which can contribute to the correct practical health measures being provided” (Wigmore, 2015:2).

4.2 Theme One: Mistrust, Fear and Rumours

Fear was cited as a major barrier to TSB throughout key-informant interviews and literature analysis. Participant six articulates the multi-faceted nature of fear during the epidemic:

“I think there was this real fear attached to having the symptoms, fear about what would happen when you went to hospital, fear you wouldn’t have access to your family, fear that maybe you didn’t have Ebola but you’d go to the hospital and then would contract Ebola”

Fear was an intrapersonal response to an uncertain disease trajectory with high mortality. This was compounded by historical mistrust of the health system, government, and international organisations (de Waal, 2014; Wigmore, 2015; ACAPS, 2016). Key-informant four describes this:

“There was a distrust of foreigners coming in and telling [them] what to do, why would you change your centuries old funeral rites process when some white person comes and says ‘you’re not supposed to wash your relatives because you’re going to die’?”

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:

“There was a lot of beliefs that Ebola was 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 government.”

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:

“The messaging we were using was really poor, it was like 95% of people will die of Ebola and...that’s not how you get people to go to seek care, that’s how you get them to stay home because they might as well stay home if they’re just going to die anyway...I think at the beginning we...were pushing fear.”

Key-informant three, who was involved in early messaging decision-making, echoed this:

“The response itself, and the early messaging of the response was quite bad...particularly the early messaging was “Ebola kills and there’s no cure” and then it says “but go to a hospital”....to say “it kills and has no cure” is not going to encourage you to want to present to a health facility.”

The early messages distributed by the official Ebola response were intended to emphasise the serious threat of Ebola and to counteract rumours that Ebola was not real (Fofana, 2014; Mark, 2014). However, because these messages adopted a fatalistic approach, they reduced people’s self-efficacy and sense of control, making TSB more unlikely (GOAL, 2014; WHO, 2015a; DuBois et al., 2015; Oxfam, 2015; Batilo Momah et al., 2016; Gillespie et al., 2016; Parker et al., 2019; Walsh and Johnson, 2018).

Another issue across the data was that messaging was naively perceived by decision-makers to be sufficient to induce behaviour change (Save the Children, 2016). This was not the case, suggesting that behaviour change is more complex than biomedical intra-personally targeted messaging. Key-informant six articulates this:

“[there was] a perception...that all you need to do is come up with the right message and push it and that alone will change behaviour, and we know that behaviour change is a lot more complicated than that.”

Messaging as a facilitator

As the limits of biomedical messaging became recognised, the perceptions of recipients were considered and messaging became more discursive than directive, to help people take control of their own situations. Messaging stopped promoting fear and instead tried to engage people, promote self-efficacy, and promote two-way messaging. Such changes appear to have also occurred simultaneously with improvements in the coordination of the response, allowing for more coordinated and effective messages to be disseminated at all levels of influence (ACAPS, 2015). This allowed best practice elements to be standardised, such as UNICEF’s ‘Communitation4Development’ framework which also uses a socio-ecological approach to behaviour change, reflecting a recognition of the importance of multi-level interventions (UNICEF, 2015; 2016).

For example, BBC Media Action implemented a range of radio programmes tailored to local issues, using local influencers to disseminate biomedical information in a socially acceptable way, (Hannides, 2015; Save the Children, 2016; Wilkinson, 2016) and using dramas and talk-shows (*Kick Ebola Live*) to allow people to engage with response officials and feel listened to (Gillespie et al., 2016). This allowed the response to become more responsive to people's needs and overcome rumours that prevented TSB, reflecting a more socio-ecological response to TSB (ACAPS, 2015).

“The idea with these dramas [was] to encourage discussion within households, within a family, with how people would respond to a scenario like that, rather than telling people what to do...prompting people to make their own plans within a community and in a family to think about how they would like to respond rather than kind of didactic ‘do this’ approach to communication” (Key-informant six).

4.4 Theme Three: Community Engagement

The biomedical narrative that permeated the response led to an initial de-prioritisation of community engagement in comparison to biomedical inputs as key-informant six articulates.

“...it was significantly de-prioritised after beds and burials, those were the kind of two overarching prioritises”

An embodied explanation for this is offered by key-informant two:

“...community engagement is considered the ‘fluffy’ thing that doesn’t require much technical expertise.”

However, like messaging, community engagement began to be perceived by responders as improving and facilitating TSB over time. Community engagement became more effective when the response increased coordination, such as when several international organisations created the Social Mobilisation Action Consortium (SMAC)⁴. This coordinated community engagement and produced participatory models that became national standards (ACAPs, 2015; SMAC, 2015). This highlights a movement away from solely biomedical outbreak-management.

⁴ Other organisations undertook separate community engagement activities independently.

Community engagement involved working with communities to understand subjective TSB barriers and facilitate effective ways to promote it (IDC, 2014). A key approach was to use trusted community leaders, including Chiefs, religious leaders and entertainment influencers to convey key messages responsively (SMAC, 2015). They were also used to help facilitate community action to engage whole communities in Ebola preparedness and integrate locally accepted measures into international response techniques, which would increase self-efficacy and social capital (SMAC, 2015). Demonstrations of treatment facilities and survivors who had sought official treatment, were also used to engage communities in discussions about their fears and to improve their perceptions of TSB benefits (WHO 2015b), helping to challenge the previous power imbalance of biomedicine's top-down approach. Key-informants six and four highlight these activities and their importance:

“[SMAC was] the primary community engagement response throughout the outbreak...[SMAC] had thousands of community mobilisers essentially boots on the ground across the country, looking at Chieftain level...to support community leaders and leadership structures to develop preparedness and response plans.”

“I wouldn't say that the whole containment of Ebola in Sierra Leone was due to the community, but I think it was a critical turning point in the fight...The village headman, the paramount council...were absolutely essential in that process.”

4.5 Theme Four: Anthropologists and their research

Another recurrent analytical theme was the use of anthropologists and the Ebola Response Anthropology Platform (ERAP) to address TSB barriers through the provision of advice regarding cultural contexts and liaison with communities to understand perceived barriers (Niang, 2015; ERAP, 2019). For example, anthropologists liaised with communities and acted as a mediator to find ways to incorporate both cultural practices and biomedical appropriate responses (Anoko, 2014).

The role of anthropologists and their research was regarded as 'crucial' in a setting where mistrust between communities and responders was rife (IDC 2014), fuelled by a response that prioritised biomedical knowledge at the expense of local or cultural knowledge.

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

“[ERAP 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 effective” (IDS, 2016).

A perspective also taken up by key-informant two:

“I think [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 have religious rites as part of a burial...”

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 and that information didn't always go full circle. So 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 didn't always come”

Key-informants argued that anthropologists were more effective when “*in the room*” (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:

“If you have a family and you’ve got a fever, you’re not going to present [to a healthcare facility] if you’re the only breadwinner in your family. So, in order to persuade you to come in and get treatment...we have to provide support to your family while you’re in the centre...you have to think about these aspects, because the first part is information, the second part is behaviour. So, adjusting behaviour you need to support people because you may have persuaded somebody that ‘yes I need treatment, but I can’t leave my kids at home’.”

This was echoed by WHO (2015c):

“People cannot be expected to do as they are told if the effort leaves them visibly worse off.”

Practical needs that international responders tried to meet to enhance TSB were the provision of food, disinfectants and household goods during quarantine and the farming of fields to ensure essential harvests (Participant 1 and 2; Carter et al., 2017b; WHO, 2015c; ACAPs, 2016). This support for people’s socio-economic needs appeared to improve the willingness to seek treatment and to reduce rumours and fears surrounding Ebola and the response (Wigmore, 2015).

5.0 Discussion

In many ways these findings lend support to, but make explicit, the various TSB barriers and the methods used to address them during the Ebola outbreak, previously implicit in both the grey literature (e.g. Wilkinson, 2016) and existing qualitative evidence relating to specific communities (e.g. Carter et al., 2017a; 2017b; Kodish et al., 2018).

However, this dissertation also builds on the extant literature to highlight the pervasive influence of dominant health narratives and ideology and how they can shape, often unconsciously, TSB and international responses. Changing health narratives during the Ebola outbreak were found to have a powerful ideological influence on TSB barriers created by fear, rumour, mistrust and messaging which when viewed from a socio-ecological lens had a multilevel intra-inter and community level behavioural influence.

Interestingly, the reification and hegemony of the narrowly conceptualised biomedical narrative at the outset, while well intentioned, failed to facilitate TSB as it silenced and trivialised alternative narratives embedded within local community cultures. It also failed to recognise that health behaviours, and by implication TSB, are, as Kelly and Barker (2016) identify, ingrained in people's everyday lives, routines and habits which help define who they are, thus helping define their sense of self. From a social practice perspective, outlined in the theoretical framework, it also fails to recognise the important influence of socially shared meaning in directing health behaviour (Shove et al 2012). Wigmore (2015) and DuBois et al. (2015) raise the point that this emphasis on biomedical approaches reflects a pattern in global perceptions and hierarchies of knowledge, whereby Western knowledge is prioritised, and non-Western tradition is negatively juxtaposed against Western 'facts'.

However, these findings also identified a temporal dimension in which the biomedical narrative was increasingly challenged, albeit not entirely replaced, with a more socio-ecological one. This appears to have been dependent on the ability of the international response to critically reflect on the effectiveness of their 'taken-for-granted' practices which was in turn influenced by the ongoing anthropological research raising awareness of 'different voices' provided it was quickly disseminated and easily available to responders. Shove et al.'s (2012) social practice model would argue this was effective because it highlighted socio-cultural 'meaning' of health to enable the response to address this.

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 have argued that mistrust and fear were also barriers in other Ebola-affected countries (e.g. (Liberia and Guinea) WHO, 2014; Cheung, 2015; Oxfam, 2015; (Nigeria) Bali et al., 2016; (DRC) McKenzie and Swails, 2019). In fact, Wilkinson et al. (2017) argue that mistrust and fear may have been higher in Guinea, due to its ethnic-political history dynamics that caused more historic antagonism between outsiders and rural communities compared with Sierra Leone.

Interestingly, rumours by the media were argued to be prominent barriers to the effectiveness of the overall response during the outbreak, and discourse at times often implied community irrationality (Mark, 2014; Thompson, 2014; Japan Times, 2015; Mazumdar 2015). However, Wigmore (2015) critically argues that rumours may have been a rational reaction to the outbreak given Sierra Leonean's historical socio-economic and political experiences.

The use of fear appeals, as evidenced in earlier messaging, assumes that when emotionally confronted with personal risk and the negative effects of their current behaviour, people will change their behaviour to reduce the risk in line with risk perception theories (Kok et al., 2018). However, this study highlights that fear was a TSB barrier. Indeed, Ort and Fahr (2018) caution against the widespread but fallacious notion that scaring and threatening people leads to behaviour change. For example, both Kok et al's (2018) and Ort and Fahr's (2018) research found that promoting self-efficacy was more effective in facilitating change than the use of threats. From a socio-ecological perspective this appears to be influential in TSB at the intrapersonal level and from a social practice approach in terms of enhancing similar intrapersonal 'competence'.

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-informants and grey-literature used in the data collection argue that these messaging techniques (following the initial failures) were successful. However, Gillespie et al. (2016) and Saiz-Bermejo (2016) highlight potential limitations to these techniques, including their involvement of women. For example, radio call-ins were usually facilitated by male influencers with male callers, implying that there may have been some exclusion of women in dynamic messaging techniques (Gillespie et al., 2016). Similar findings were also found in Liberia (Peters, 2014) indicating a widespread limitation to messaging effectiveness.

This divergence between the research findings and other literature is likely to have occurred due to the methodological choice of collecting data (interviews and literature) from responders themselves regarding the response they were involved in. Whilst key-informants were surprisingly self-critical and self-reflective, this lacked in reference to messaging. However, it is important to note that this study did not intend to be evaluative and thus the potency of responder bias was negated, but it did mean that critical analysis of impact was difficult to infer.

5.3 Theme Three: Community Engagement

Community engagement activities that the international response undertook can be interpreted as community, interpersonal and intrapersonal level interventions to address TSB barriers within the socio-ecological framework. Community engagement was intended to positively influence people's knowledge, their social networks' perceptions and the rules and norms that regulate communities, all of which influence health behaviour and therefore, TSB. This reflects a multi-level behavioural change approach.

Community engagement activities, including use of community leaders and listening to communities, were employed to understand the TSB barriers generally, to address fears of treatment facilities, convey messages through trusted sources, and to address perceived culturally inappropriateness of the response through support to community leaders to adapt cultural norms and rules and create locally appropriate responses to Ebola.

Using community leaders was founded in the belief that such leaders are trusted and have influence over the social rules and norms; potent health behaviour influences (McLeroy et al., 1988). From a social practice perspective, they have the potential to provide the necessary 'materials', reflect shared cultural norms and help facilitate 'competence' required for behaviour change (Shove et al., 2012), highlighting how the international response tried to address TSB barriers.

Both the literature collected, and key-informant interviews reveal a positive emphasis on the role of community leaders. However, this positive perception is uncritical of the design of community-engagement interventions including the choice of community leaders, since communities are rarely homogenous and contain multiple cultures (Wilkinson et al., 2017).

By defining community leaders from the perceptions of responders, which was often rooted in top-down administrative conceptualisations, Wilkinson et al. (2017:5) argue this “glossed over” other, and sometimes *more*, influential and legitimate ‘leaders’. Parker et al. (2019) suggest that the chieftaincy system is highly contentious in areas of Sierra Leone and this administrative approach to conceptualise ‘leadership’ led to resistance in areas with historical antagonistic relations with Chiefs.

The use of illegitimate community leaders and the implications this had for TSB feature prominently in literature pertaining to other outbreak-affected countries including Guinea (Anoko, 2014) and Liberia (Peters, 2014). Nonetheless, whilst misgivings were briefly raised about the types of leadership engaged in two key-informant interviews – with key-informant two admitting that they “over relied on traditional leadership” – most of the data collected remained uncritical of the design of engagement methods.

5.4 Theme Four: Anthropologists

Theme four documented how anthropology/-ists were used by the international response to understand TSB barriers, liaise between communities and the response and thus implement more effective strategies to promote TSB.

For example, the overarching theme of biomedicine was perceived by communities as culturally insensitive and thus not always appropriate to comply with. Interventions like biomedical burials without traditional rites went against communities’ cultural rules (Richards et al., 2015). These rules are a community-level behavioural influence on individual decision-making, according to the socio-ecological framework and reflect influential ‘meanings’ from a social practice perspective (McLeroy et al., 1998; Shove et al., 2012). Thus, people did not want to seek treatment as, if they died in a facility, these important cultural rules would not be observed (Richards et al., 2015).

Through a socio-ecological lens, anthropologists, as an intervention, were targeting community and interpersonal influences (McLeroy et al., 1988) as anthropologists liaised between communities and the biomedical response to facilitate cultural rule adaptation and integrate some cultural elements into infectious control procedures (Quick and Fryer, 2018). This transformed community-rule constraints on TSB into promoters.

The involvement of anthropologists in improving response effectiveness across West Africa is viewed positively and is well-documented elsewhere (Chandler et al., 2015; AAPPG, 2016; Gillespie et al., 2016; Whitty, 2017) particularly in Guinea (Anoko, 2014; Fassassi, 2014; Allagier and Svalastog, 2015; Wilkinson et al., 2017). However, there is clear discourse divergence between this and key-informant responders, who were more critical of anthropologist's impact in Sierra Leone. Anthropologists came late in the outbreak and there were dissemination issues with their findings: research was too slow and wasn't reaching front-line workers because not all were in Sierra Leone and their findings had to 'trickle down' from policy advisors in Whitehall.

Therefore, a better response model might incorporate anthropologists formally into the response system and provide them with crisis training to adapt anthropological techniques to 'fast-pace' crises, to ensure quicker results dissemination, akin to Laverack and Manoncourt's (2015) suggestions. Having anthropologists '*in the room*' in the affected country, liaising with policymakers *and* implementors would also ensure faster applications of findings.

Whilst the use of anthropologists to engage with and listen to communities has been praised for helping inform the response (Gillespie et al., 2017), they were not the only ones doing this, trained community mobilisers did too (SMAC, 2015). Thus, whilst anthropologists may provide important insight for the response, anthropologists should not be seen as the *only* 'listeners'. In fact, key-informants repeatedly suggested that everybody in the response, regardless of roles should 'listen more'.

5.5 Theme Five: Addressing Livelihoods

Theme five highlights the methods the response implemented to encourage TSB by addressing people's socio-economic needs had previously prevented TSB due to the dominant biomedical narrative. Wigmore (2015) argues that this contributed to reducing non-compliance with health interventions.

This highlights a recognition of two things: that the provision of biomedical interventions and information concerning the benefits of such treatment is insufficient to promote behaviour change, and that a gap remains between intentions and behaviour concerning seeking treatment. For example, despite a move to more effective messaging techniques over the course of the outbreak, which were more successful in persuading people of treatment benefits, this did not necessarily translate into actualised treatment-seeking.

Behaviour change and health promotion literature detail that whilst people may acquire knowledge of the benefits to certain health behaviour (e.g. treatment) and intend to change their behaviour accordingly, some people are unable to actualise this intention (Sheeran, 2002; Sniehotta and Schwarzer, 2005; Faries, 2016; Sheeran and Webb, 2016). Reasons highlighted in the findings were mostly material not cognitive and included: lack of childcare, lack of resources during quarantine and risk of future livelihoods (e.g. harvest failure). For example, treatment could save a person's own life but if they sought treatment, their children may die from starvation. From a social practice perspective this reflects the necessary 'materials' required for successful behaviour change as well as giving 'meaning' to people's social role identity (Shove et al., 2012). Improving 'material' needs, improves intra-personal self-efficacy facilitating TSB under the socio-ecological framework (McLeroy et al., 1988). Thus, explaining how addressing livelihoods helped to address the barriers to TSB.

However, as noted, these actions were not a panacea for TSB, as there were many barriers to TSB across many influence levels (McLeroy et al., 1988). Whilst the international response showed commitment to providing material support, there were still coverage and quality issues, particularly as resources and coordination were initially slow. For example, Street Child (2015) found that even halfway through the outbreak, some rural communities were not receiving livelihood support to facilitate TSB.

6.0 Conclusion and Implications

This dissertation has sought to understand, from the perspectives of the international response:

- *What were the barriers to treatment-seeking behaviour during the Ebola outbreak in Sierra Leone?*
- *How did the international response address these barriers?*

By applying a dual qualitative methodology of secondary literature analysis and key-informant interviews analysed thematically, this dissertation found that: fear, mistrust and rumours; initial messaging; livelihood concerns; underpinned by a dominant biomedical health narrative whose dominance also fuelled culturally insensitive interventions, were potent TSB barriers during the Ebola outbreak. Using the Socio-Ecological and Social Practice Model frameworks, this dissertation analysed how these factors became TSB barriers.

Additionally, this dissertation found that despite the initial dominant biomedical health narrative there was temporal understanding within the international response that increasingly recognised biomedicine's limits and that a successful response needed to address multiple influences of health behaviour more socio-ecologically, to ensure TSB. Thus, the international response attempted to address TSB barriers targeting multiple influences at intra-inter and community levels, addressing 'materials' 'meanings' and 'competence' behavioural elements, as outlined in the socio-ecological and social practice frameworks. For example: by improving dynamic messaging and community engagement to facilitate self-efficacy, using anthropologists to understand barriers and to create culturally appropriate biomedical interventions, and the support of livelihoods to address TSB's intention-behaviour 'gap'.

This research has several implications including the recognition of the value of integrated research and anthropology within outbreak responses. Additionally, that people need to be reflective of the health narrative they are using and how this impacts health intervention success.

Future research could compare multiple perspectives of TSB and attempts to address them, to better inform future best-practice. Adding to this, further empirical research evaluating the international response's attempts to address TSB barriers is also salient. Given the ongoing Ebola outbreak in the DRC, future research could also compare the barriers and attempts to address them between this and the Sierra Leonean outbreak, to infer whether 'lessons' have been learnt.

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:

“the biggest challenges in an Ebola response are social rather than medical...”

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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Appendix 1: Search Strategy

Source Type	The source was published in a <ul style="list-style-type: none"> ▪ Scholarly and peer reviewed journal or academic book ▪ Doctoral thesis ▪ Grey literature
Availability	Full text
Language:	English
Publication period:	2014 (outbreak start) – onward (several years post-outbreak). <i>NB: This allowed for a temporal dimension to be analysed, to discover potential changes in the types of barriers to TSB and methods to address them over the course of the outbreak.</i>
Search Terms/Boolean logic	Databases
‘Sierra Leone + Ebola’	Academic Search Complete
‘Treatment seeking behaviour’	ETHos – UK
‘Barriers to treatment seeking behaviour’	JSTOR
‘Ebola + Response + Sierra Leone’	Google Scholar
‘international response +ebola+Sierra Leone’	Medline Complete
‘SMAC’	PubMed
‘Community Engagement + Sierra Leone + Ebola’	Sage Journals Online
‘WHO Anthropologists’	Science Direct
‘Social Science + Ebola’	Springer Link
‘Ebola Biomedicine’	Taylor and Francis
‘Anthropology + Ebola’	Web of Science
‘Ebola rumours’	
‘Ebola social mobilisation’	
‘NERC + Ebola’	
‘Ebola Messaging’	
‘International Response + Ebola NOT Guinea Liberia’	
‘Culture + Ebola’	
‘Behaviour change + Ebola’	
‘Health Communication*’	
‘Infectious disease response’	
‘Ebola treatment’	
‘Ebola Humanitarian Intervention’	

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?

The records from this study will be kept confidential. Only I (the researcher) will have access to any audio tapes and files relating to the project. Your data will be anonymised, and your name will not be used in any publication resulting from this study.

All files, transcripts and summaries will be coded and stored separately from any names of other directly identifying attributes of participants. Any hard copies of research information will be kept in locked files at all times.

If you wish to access the personal data that you have provided, this can be requested. This can only be supplied to the participant who originally provided the data.

What if I have a question or complaint?

If you have any questions regarding this study please contact the researcher, Natasha via email: n.i.glendening@lse.ac.uk.

If you have any concerns or complaints regarding the conduct of this research, please contact the LSE Research Governance Manager via research.ethics@lse.ac.uk.

If you are happy to participate in this research study, please complete the attached consent form.

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: _____

Signature: _____ Date: _____

Interviewer name: _____

Signature: _____ Date: _____

For more information, please contact: Natasha Glendening, n.i.glendening@lse.ac.uk

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 to 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 liaise 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	<ul style="list-style-type: none"> ▪ Transcribing (verbatim), reading and re-reading data sets ▪ Noting down initial themes
2.	Generating initial codes	<ul style="list-style-type: none"> ▪ Systematically coding interesting features in the entire data set ▪ Collating data relevant to each code
3.	Searching for themes	<ul style="list-style-type: none"> ▪ Collating codes into potential themes ▪ Gathering all data relevant to each potential theme
4.	Reviewing the themes	<ul style="list-style-type: none"> ▪ 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”
5.	Defining and naming the themes	<ul style="list-style-type: none"> ▪ Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells ▪ Generating clear definitions and names for each theme
6.	Preparing the findings and discussions	<ul style="list-style-type: none"> ▪ Selection of vivid, compelling extract examples ▪ Final analysis of selected extracts, relating the analysis back to the research question, theoretical frameworks and literature

Appendix 6: Interview Extract

I: Which is intriguing...Next question, so yeah, so you said there was this community engagement and lots of people were trying to do it even if they weren't doing it that well, what type of methods were they trying to use for this?

P2: I mean as things got better some really clear models that came out so for example, I'm sure you've heard of SMAC, Social mobility Action Consortium, that was a very clear model of kind of multi-channel, meaning we spent, using radio, using on the ground youth actors, to do participatory community led development of prevention plans, big thing with pastors or Christian and Muslim religious leaders, as well as kind of making big billboards of posters and stuff like that. So, there was this, and that was a very clear model that became almost the national model for how to do this. And you know SMAC and the social mobilisation pillar worked with all actors whether or not they were SMAC related or not to develop SOPs, for you know what is a community engagement actor, how did they work you know, they should be working 3-5 days a week, they should be getting at least a 2 week long training, to be, they should be having access to updated messaging, they should have been feeding what they hear from the community back up so we can adjust the messaging and send it back down, they need to be paid, like there's a lot of very clear guidance about what that looks like. But I mean that probably didn't come for 8 or 9 months into the outbreak, if the outbreak started like in what April. It took a really long time, and I think that's because community engagement is considered the 'fluffy' thing that doesn't require much technical expertise which is crap of course it does, and you can't just assume that you get 50 people in a room that and give them a 2 hour training that they can go out and be community mobilisers, that's not reality. But there was a real interpretation that oh this is super easy anybody can do it and that took a lot of time to try to get people away from.

I: So do you think that they improved over time the messaging on behaviour change?

P2: Uh yeah, absolutely. I mean we got away from 90% of people are going to die to the earlier you seek care the better, seeking care means you'll get tested and this means, how to prevent Ebola, you know handwashing is really important, don't let sick people into your village, if somebody gets sick call 117, funerals are dangerous, everybody needs to have a safe and dignified burial. I mean as these things, we got better with the messaging and it got better sort of directed to things people could actually do as opposed to things that they couldn't do. I think at the beginning we asked, we weren't pushing action-orientated behaviour change, we were pushing fear. And as it got better, it got a lot better, you know the SMAC model was used, they'd go into a village and they wouldn't tell...