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The 2014-2016 Ebola Epidemic in West Africa

How did cultural factors contribute to an escalation of the outbreak?

—
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Preface

Ever since my second year of medical school, I have been engaged in different volunteer organizations and projects working on global health. I have had the opportunity to travel to other countries and meet students from all over the world. Through different meetings and projects, I have had the opportunity to exchange experiences, ideas and culture. I have seen how different, but also how similar practices can be across the world. It is because of all this that I have developed an interest for the differences we see in healthcare systems in the world today.

When we hear about diseases like for instance Ebola on the news in Norway, it is very easy to draw conclusions and create prejudices. People ask themselves questions like; why do they not do what is necessary to stop the epidemic? Why do people keep caring for their loved ones at home knowing it is against medical advice? Do they simply just not know any better? I was sure there was another explanation for why people did what they did. I started reading about the 2014-2016 Ebola outbreak in West Africa, and it seemed that in a lot of cases, transmission happened because of cultural rituals and customs. This made me curious. How does one case of Ebola transmitted from a forest animal to a child cause almost 29 000 cases and more than 11 000 deaths? What are the main reasons that this Ebola epidemic became bigger than any previous ones?

I would like to thank my thesis advisor professor Ørjan Olsvik at the University of Tromsø, for his great commitment to the topic. His willingness to share his own knowledge and experiences has been very inspiring. His input has been of great value throughout this process.

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Summary

Background

The 2014-2016 Ebola epidemic is the biggest known outbreak since 1976. The transmission from a bush animal to one human eventually caused 28 652 cases and 11 325 deaths. It is necessary to investigate how one case could cause that many infected people and deaths, and this study aims to identify the most important cultural factors that contributed to these high numbers. Why did people hold on to their rituals despite being warned about the risk of transmission? How did fear and stigma contribute to an increased rate of transmission? How can we better prepare to tackle these cultural factors in case of a new epidemic?

Method

This thesis is a literature review, mainly based on studies conducted during or after the 2014-2016 Ebola epidemic in West Africa. The articles were found using PubMed and using the references of these articles for further reviews. All articles somehow highlight cultural aspects of the 2014-2016 epidemic, except for two articles. The results of these articles have been compared and seen in a cultural context.

Results

Burials and funeral rituals has had an impact on the transmission of EVD, and it is estimated that without SDBs there would have been 1 411 to 10 452 cases more. People who had contact with an infected person both before and after death had a 2,63-5,97 times higher chance of being infected, compared to those who only had contact after death. Survivors mentioned that messages conflicting with their culture were difficult to follow. Fear and stigma played a part in making people avoid healthcare facilities.

Conclusion

Cultural factors such as burials and funeral rituals, caregiving, fear and stigmatization and communication conflicts have definitely had an effect on the transmission of EVD. To prevent this in a potential new outbreak, it will be important to understand the cultural context of the epidemic, and intervene thereafter.

Abbreviations

ALT	Alanine aminotransferase
AST	Aspartate aminotransferase
CDC	Centers for Disease Control and Prevention
DRC	Democratic Republic of Congo
ELISA	Enzyme linked immunosorbent assay
ETC	Ebola Treatment Center
EVD	Ebola Virus Disease
MSF	Médecins Sans Frontières
ORS	Oral Rehydration Salts
PCR	Polymerase chain reaction
rVSV-ZEBOV	Recombinant vesicular stomatitis virus-Zaire Ebola virus
SARS	Severe acute respiratory syndrome
SDB	Safe and dignified burial
WHO	World Health Organization

Introduction

Background and purpose

In the period from 2014-2016 the world witnessed the biggest known Ebola epidemic so far. The first case, called the index case, is thought to be an 18 month old child in Guinea (1). From there the disease spread to several different countries, mainly affecting Guinea, Liberia and Sierra Leone. A total of 28 652 people were infected and 11 325 people died of Ebola virus disease (EVD) (2). It is believed that the index case was the only case where transmission happened from animal to human, so called zoonotic transmission. All other cases happened through human to human transmission.

The international response to the Ebola outbreak was slow in the beginning. For the first months, Médecines Sans Frontières(MSF) were the only ones working to stop the disease from spreading and to treat the victims (3). Travelling to a different country and meeting people there while they are at their most vulnerable can be a big challenge in itself. In the case of Ebola you do not have a lot of time to prepare before you leave your home country. You do not get the chance to understand how the healthcare system works or which cultural factors you need to consider when you are offering people help. Their understanding of disease might be completely different from yours and the way they choose to handle it might be difficult to cope. This can become a challenge when your way of doing things happens to be offensive or hurtful to the person you are trying to help. This was sometimes the case in the 2014-2016 Ebola outbreak. So called “outsiders” went to the affected countries, wanting to help, but in some cases also caused harm. In the end the overall goal should be to minimize the damage and to cause no harm.

The intention of this paper is to highlight some of the cultural factors that caused conflict between the ones trying to help and the ones needing help. Which were the most common cultural rites and rituals causing EVD transmission during the 2014-2016 Ebola epidemic? Why did people hold on to their rituals despite being warned about the risk of transmission?

How did fear contribute to an increased rate of transmission? What went wrong in the attempt to change high risk behavior, and how can we better prepare to tackle this in case of a new epidemic?

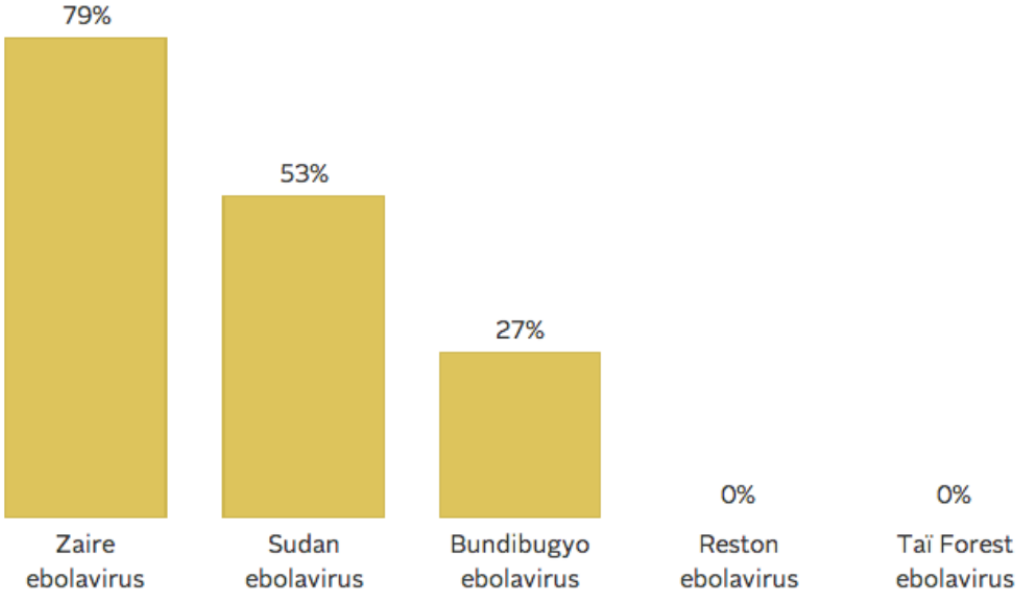
No ethical conflicts are related to this paper.

Ebola virus disease

The virus

The Ebola virus was first discovered in 1976, when there were two outbreaks at the same time in areas that today belong to South Sudan and the Democratic Republic of Congo(DRC). The virus has gotten its name after the Ebola River in DRC. There have been several smaller outbreaks since 1976, but the most comprehensive occurred in West Africa in 2014-2016 (4). The Ebola virus belongs to the Filoviridae family, which consist of the Ebola virus, Cuevavirus and Marburgvirus (4). These viruses are single-stranded, negative sense RNAs. They can all result in hemorrhagic fever and severe illness in humans and other primates. There are five known species of the Ebola Virus; Zaire, Bundibugyo, Sudan, Reston and Tai Forest (5). The 2014-2016 Ebola outbreak was caused by the Zaire virus; the Ebola virus with the highest lethality rate (figure 1) (4).

Figure 1. Lethality of the five Ebola virus species



Transmission

Primary transmission of the Ebola virus happens from an infected bush animal to a human. Bush animals, like for example fruit bats, can be carriers of the virus without being sick, and therefore make up the reservoir of the Ebola virus. Transmission happens through contact with blood, secretions or other types of bodily fluids, or with organs, as well as contact with contaminated surfaces and materials (4). This kind of transmission from animals to humans is called zoonotic transmission (6). The disease can then spread from the primary case to other humans. This happens through the same source of contact as between animal and human, and can also occur through sexual contact. The significance of this is still not completely understood, but the possibility of sexual transmission was suspected during the Ebola outbreak in 2014-2016. It is not certain how long the virus can survive in semen and sources of transmission. However, there has been a case of transmission 6 months after onset of symptoms and studies have shown that the virus can be detected in semen as long as 9 months after onset (7).

The incubation period for the Ebola virus is between 2 to 21 days, meaning it will take 2 to 21 days from a person has the virus in their body until they start showing symptoms. The virus can not transmit to another person until the infected person has symptoms of the disease. If a person survives the disease, they are still infectious until their blood no longer contains the virus (4). People at particularly high risk of transmission are people in close contact with sick people or the bodies of Ebola victims after their death. This includes health care professionals, family members and relatives, or community members caring for the sick, as well as people taking care of the deceased and their burials. It is therefore highly important that these people have knowledge about infection control and what measures are necessary to stay safe of transmission (4).

Clinical features

The Ebola virus can give very severe illness and has a very high lethality. However, in the early stages it can show a similar clinical presentation as a lot of other common diseases occurring in the same geographical areas. These symptoms include fever, fatigue, headache,

myalgia and sore throat. It will therefore be difficult to clinically distinguish Ebola from other tropical diseases such as malaria, typhoid, Lassa fever and meningitis (4). After a while more serious symptoms portray, such as vomiting, diarrhea, rash and symptoms of reduced kidney and liver function. In severe cases infected people can have internal or external bleeding, often presenting as bleeding from the gums, bruising or bloody stools or vomit. These are the symptoms that clinically separate EVD from other infectious diseases. However, even at this stage the symptoms may be similar to those of Lassa fever, another hemorrhagic fever illness which is endemic in West Africa (8). Possible, serious complications of EVD include coma, seizures, shock, severe bleeding and multiple organ failure (9).

A study conducted after the 2014-2016 Ebola outbreak, showed that one of the most important measures to prevent further spread of the disease, was early diagnosis (10). To confirm an EVD case laboratories can use either the patients’ whole blood or, when this is not possible, like for example in deceased people, oral fluid specimens (4). There are several ways of diagnosing the disease, and the different diagnostic tools have different value throughout the progression of the disease. Table 1 shows what tests should be used at the different stages of the disease (11).

Table 1. Diagnostic tests of EVD

Timeline of Infection	Diagnostic tests available
Within a few days after symptoms begin	<ul style="list-style-type: none"> - Antigen-capture enzyme linked immunosorbent assay (ELISA) testing - IgM ELISA - Polymerase chain reaction (PCR) - Virus isolation
Later in disease course or after recovery	<ul style="list-style-type: none"> - IgM and IgG antibodies
Retrospectively in deceased patients	<ul style="list-style-type: none"> - Immunohistochemistry testing - PCR - Virus isolation

Source: CDC

Treatment and prevention

There is no cure for or treatment of the Ebola disease itself. However, symptomatic treatment and oral or intravenous fluids have been proven to have an effect on survival. Trials using blood products, immune therapy and drug therapy are being conducted, but none has yet showed significant effect on the disease (4).

A study conducted in a UK military Ebola treatment center in Sierra Leone used a standardized treatment bundle, supplemented by individual needs of each patient. Included in the basic treatment were parental fluid and electrolyte replacement therapy, stress-ulcer prophylaxis, empirical ceftriaxone and antihelminthic drugs and analgesia. 50 % of patients also received blood products. Although available resources in this treatment center might have been better than elsewhere, case fatality rate were lower than in comparable studies: *“A clinical prioritization score developed by Hartley et al., adjusted for age and viral load predicted a case fatality rate of 62% in our cohort (95% CI 45%–74%) at admission. The case fatality rate in the military EVDTU was 49% (95% CI 33%–65%) overall, but direct comparison of clinical outcomes from different treatment facilities has proved difficult. Rates reported from other ETCs in Sierra Leone were similar from cohorts with lower median ages and higher Ct values. International Medical Corps reported a case fatality rate of 58% (95% CI 53%–64%, median Ct 25.4), and Mediciens san Frontieres, a case fatality rate of 51%(95% CI 47%–56% [...]”* (12).

The study mentioned in the section above also showed that there was a positive preventive effect of isolating individuals who had been in risk of infection until test results came back, and in case EVD was confirmed, isolation throughout the treatment course. Other measures that prevented further transmission was decontamination of the deceased Ebola victims' bodies as soon as possible, use of condom after recovery from the disease and prevention of importing people sick with Ebola or quarantining these (10).

Vaccine

Before the 2014-2016 Ebola outbreak there was no effective vaccine against the disease. Towards the end of this outbreak a flare-up was reported in Guinea. By this time an experimental vaccine had been developed, but had still not been tested in clinical trials. This was the recombinant vesicular stomatitis virus-Zaire Ebola virus(rVSV-ZEBOV) vaccine. The World Health Organization (WHO), Gavi and the World Food Programme funded a ring vaccination in response to the flare-up of Ebola in Guinea, and later on evaluated the safety of it and the short term side effects (13). Ring vaccination is a strategy that was also used in the eradication of smallpox. This is done by identifying and vaccinating contacts and contacts of contacts of infected people. This way a buffer is created around the infected person, so that chances of transmission to the rest of the society are decreased (14). During one month, 1510 people were vaccinated and none of these were infected by EVD. Amongst people between 6-17 years 17 % experienced side effects, but all of these were mild. Among the vaccinated adults 36 % experienced side effects, 98 % of these were characterized as mild. No severe effects were reported (13). However, this was potentially risky, as both the short and long term side effects of the vaccine were unknown at the time.

Prognosis

Ebola virus disease is a serious illness, with case fatality rates ranging between 25-90 % (4). A lot of different factors affect the outcome for the patients. Many studies show a strong association between fatality and high viral load in blood (15). Coinfection with malaria increased the fatality from 58 % to 86 %. Damage to the liver, measured by levels of aspartate aminotransferase (AST) and alanine aminotransferase (ALT), as well as high levels of CRP and IL-6 also increased the risk of death (16). *“Factors such as high blood viral load, confusion, abdominal pain, vomiting and conjunctivitis were associated with poor prognosis for EVD patients”* (15).

A clinical study conducted in a survivor clinic in Sierra Leone, aimed to map the different long term post-infection complications. The study included 1001 medical consultations divided on 166 patients. They did the following findings: *“The most frequent complaints and diagnoses*

were arthralgia (n = 129 [77.7%]), fatigue (n = 116 [69.8%]), abdominal pain (n = 90 [54.2%]), headache (n = 87 [52.4%]), anemia (n = 83 [50%]), skin disorders (n = 81 [48.8%]), back pain (n = 54 [32.5%]), and alopecia (n = 53 [31.9%]). Ocular complications were diagnosed in 94 survivors (56.7%); uveitis was the most common (n = 57 [34%])” (17). The same study also examined the survivors’ mental health and found that 27 % were ashamed or embarrassed by the fact that they had been infected with the disease, 26 % felt that others were avoiding them even after being declared non-contagious. 18 % had trouble falling asleep at night (17).

The 2014 Ebola outbreak in West Africa

The beginning

The first suspected case of Ebola, called the index case, is believed to be an 18 month old boy in Meliandou village in Guinea. He presented with fever, dark stools and vomiting on the 26th of December 2013. The source of transmission was probably wild animals, as this happened in a forest area. The boy died after 2 days of illness. By mid-January 2014 several of the boy's closest family members and different health care professionals nearby reported similar symptoms. On the 24th of January an alert was made about 5 cases of severe diarrhea with rapid deaths. Cholera was suspected as the cause. On February 1st an infected person travelled to the capital of Guinea, Conakry, where he died of the disease in a hospital. Throughout February several cases of the same disease popped up in several new places. On the 13th of March the WHO was alerted and an Emergency Management System was opened. At this point Lassa fever was suspected. Three months after the symptoms presented in the index case, on March 22nd, laboratory investigations confirmed that the epidemic was caused by the Ebola virus, more specifically the Zaire species. By then 49 people were reported sick and 29 people had died (1).

Outbreak response

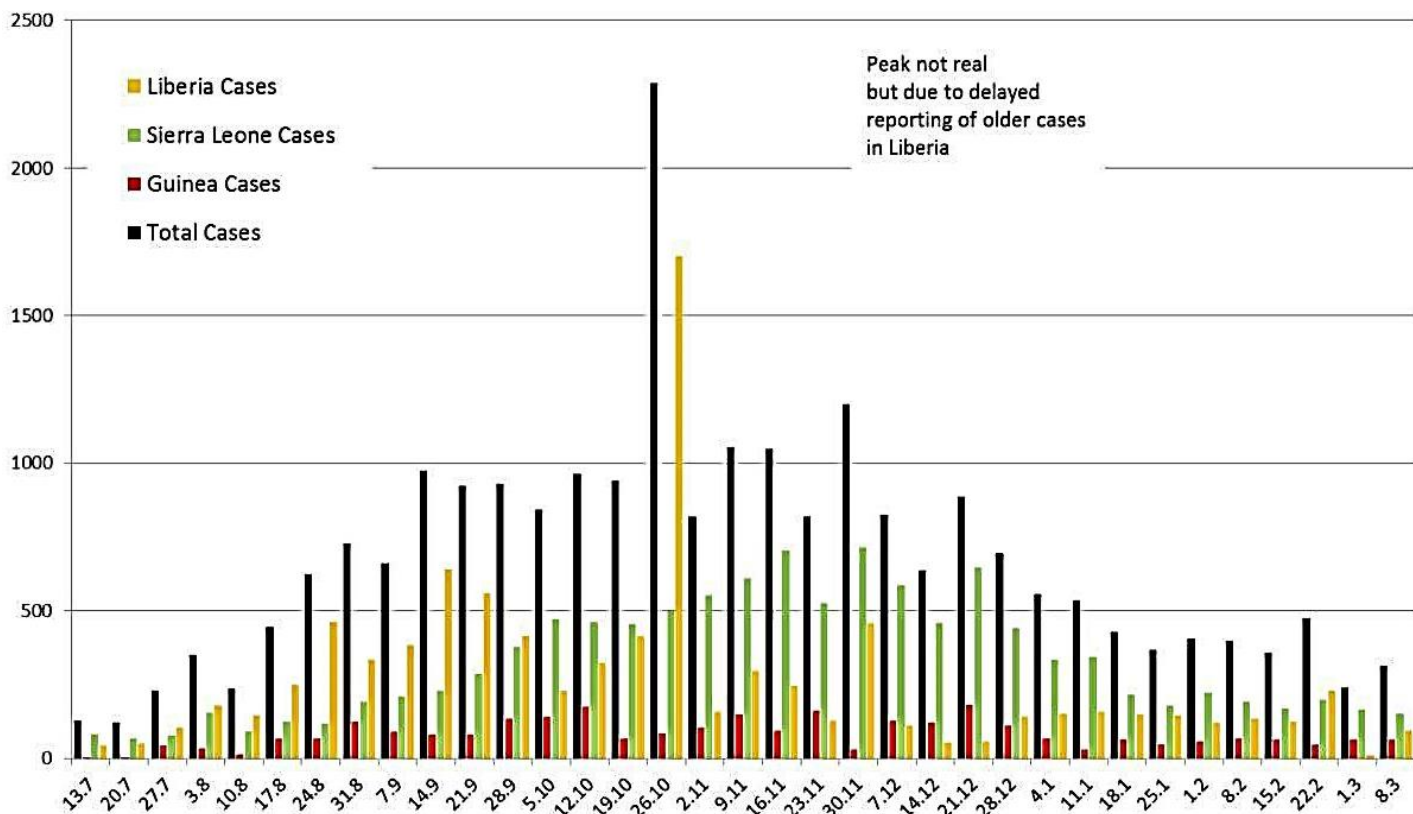
The 2014-2016 Ebola epidemic demanded a huge international humanitarian response. MSF were one of the most important contributors in the war against Ebola; 1/3 of all confirmed Ebola virus disease cases were treated by MSF (18). In the beginning, MSF was the only

provider of aid for the Ebola victims. Time passed before the rest of the world community responded. Only after an increase in cases in August 2014, five months after the outbreak was confirmed to be caused by Ebola, did the rest of the world open their eyes to it. At this point MSF had already exceeded their capacity, and had to prioritize their resources (3). The response included a lot of different interventions in different parts of the society and can be categorized in five different main categories: i) surveillance, contact tracing and case investigation, ii) Case management, iii) Safe burials, iv) Social mobilization and community engagement, and v) Delivery of basic services (19).

The biggest outbreak so far

There are several reasons why the 2014-2016 Ebola outbreak became the biggest known outbreak so far, with 28 652 total cases and 11 325 deaths (2). As described earlier it took months before the epidemic was identified as Ebola, and by that time the disease had already spread from Guinea to Sierra Leone and Liberia. Most previous outbreaks have happened in equatorial Africa, and their health care professionals are therefore more aware of what symptoms to look for and they are better prepared to tackle an outbreak. Health care professionals in West Africa on the other hand, were not familiar with the disease, and Ebola was therefore easily confused with more common illnesses in the area. Ebola was “*an old disease in a new country*”. This was also evident when it came to the general public; people were not familiar with this disease and the public health response measures were new to them. Also new to this outbreak was that it was now also present in urban areas, and it was spread to other continents by international air travel (1).

Figure 2. Reported cases per week from July 2014 to March 2015



https://commons.m.wikimedia.org/wiki/File:West_Africa_Ebola_2014_13_Reported_Cases_per_Week.png

Even before the Ebola outbreak started in 2014, the health care systems in Sierra Leone, Guinea and Liberia were facing a lot of challenges. The countries and their infrastructure were still recovering from the recent civil wars. With an average of 1-2 physicians per 100 000 population before the outbreak, there was already a lack of health care professionals. This was also a particularly vulnerable group, especially in the early stages of the outbreak, as they were treating patients without knowing what they were dealing with and without the use of proper protection (1).

Because of the low access to health care and the skepticism and fear of seeking modern health care, people tended to avoid this and rather took care of their loved ones themselves or sought help from traditional healers. This, in fact, became a source of transmission itself. Another important transmission route was funerals and burial rituals. In fact, the WHO estimated that as much as 80 % of Ebola virus disease cases in Sierra Leone were caused by unsafe burials and funerals (1). One believes the first case of Ebola in Sierra Leone was a traditional healer who was approached by infected people from Guinea. It is later estimated

that 365 deaths caused by Ebola can be tracked back to the funeral of this traditional healer (20).

Role of the media

Hearing about Ebola in the media during the 2014-2016 Ebola outbreak was inevitable. The outbreak was widely covered both locally and globally, resulting in good and bad consequences. At a local level, media was used as a communication channel to the population for information, guidance and public health messages. On the other side media could be a source of misinformation given by non-professionals, and the way the disease was portrayed encouraged the development of fear, stigmatization and panic, both in local communities and worldwide (21). One can ask if the media coverage was exaggerated when you compare it to the attention other infectious diseases get, that take way more lives than what Ebola did. For example, in about two years Ebola killed about 1/3 of the same amount of people that tuberculosis kills in one week (2,22). In other words *“coverage of Ebola by media are prolific but sometimes narrow and unbalanced”* (21).

Understanding Ebola in the cultural context of West Africa

Relevance to the 2014-2016 Ebola epidemic

It became quite evident during the 2014-2016 Ebola epidemic that culture is a factor that needs to be addressed in such circumstances, if not it can have serious consequences. In the initial stages of the outbreak, this was not considered as big a threat as it turned out to be. Certain interventions might have resulted in more harm than good, until people understood that they had to collaborate with the locals to find solutions which both paid attention to culture and preventing further transmission (23). However, passing on public health messages and getting people to understand, could be challenging in societies with low literacy rates, e.g. the literacy rate in Sierra Leone in 2013 was 35 % (24). Julianne Anoko, an anthropologist from the WHO, stated that *“The problem was that the people handling the intervention only looked at this as a health issue; they did not try to understand the cultural*

aspects of the epidemic” (24). Below are some of the cultural aspects of significance in the Ebola outbreak.

Perception of illness and caring for the sick

In several societies in West Africa people are obliged to take care of their families and relatives when they get sick or die (24). Taking the sick to the hospital or a health care center therefore is not necessarily the first thing people do. This is further strengthened by the low access to healthcare in the area, and after a while also by the rumours regarding the Ebola treatment centers. People came from the outside to treat the locals against a disease that had never been seen in the area before, wearing what looked like space suits. People who were sent to the Ebola treatment centers(ETCs) did not always come back, and the families did not know what happened to them. People therefore chose to take care of their sick family members themselves, increasing the risk of transmission. In certain communities it is believed that illness is caused by a curse and that people associated with the victim also can be cursed (23).

Rituals related to death

There is a wide specter of religions and beliefs in countries in West Africa, but common for a lot of them are parts of the rituals related to death. These are conducted by community members, with no equipment to protect themselves against possible infectious diseases. The rituals often include washing and dressing the bodies according to tradition, as well as touching and kissing the body (24). In some societies they even bathe in the rinse water after cleaning the corpses (1). This is extremely risky behavior if the deceased was infected with Ebola, as it is around the time of death that the viral load in the body is at its highest, hence the risk of transmission at this stage is high (24).

As in most cultures worldwide, burials and rituals related to death are carried out as a way of showing respect to the deceased and for the close ones to say their goodbyes (24). In some cases it is also a way of helping the dead to make the transmission into the afterlife, the lack

of such rituals would cause harm and illness to the family of the deceased (25). Other possible consequences of failure to follow tradition could be that the soul of the dead wanders the earth for eternity and troubles the community of which he or she belonged (24).

The rituals described above was seen as a huge threat by health care professionals, and health authorities expressed that all risky rituals had to come to an end. However, these messages was not received in a good manner by the locals, and looking back this is not hard to understand: *“People were expected to go from one end of the spectrum to the other; from washing the bodies by hand, dressing them, and holding elaborate ceremonies, to having a corpse in a body bag and no goodbye”*. After a while, authorities and people coming from the outside understood that they had to collaborate with the locals to find a common path to solve the issue. After explaining the great risk of transmission related to burial rituals, they came to an agreement which allowed mourners to say goodbye to their loved once in a respectful way, which also paid attention to their own safety as well as the safety of the burial teams. For example religious leaders studied their holy books and found exceptions to the rules, so that they could pray for the deceased without actually touching them and the Ebola burial teams could dress their bodies after the families’ wishes and place belongings of the dead in the bag along with them (24). According to medical anthropologists, risky behavior related to burial rituals have also been seen in previous Ebola outbreaks in Africa, but is supposed to have been exceptionally high-risk in the outbreak in West Africa (1).

Material and methods

The description of and plan for this paper was made in October 2016. The topic of Ebola was chosen, and then determined the purpose and how to target it in the best possible way. The autumn of 2017 was spent to read up on Ebola and the culture of West Africa using resources available from the WHO, MSF and Center for Disease Control and Prevention(CDC), as well as writing the theoretic part of this paper. In the period from January to April 2018 relevant articles were found, reviewed and summarized in the GRADE forms found attached to this paper. The remaining parts of the thesis were written in April and May 2018.

This is a literature study aimed to examine and review literature dealing with cultural factors that affected the size and impact of the 2014-2016 Ebola epidemic in West Africa. A semi-structured literature search was done using PubMed as the main search engine. In addition references from the articles found in the literature search were used, when relevant. All articles reviewed are qualitative studies, some having quantitative aspects. Evaluations and reports from the WHO and MSF has also been used in the discussion part of this thesis. The literature search was ended when the findings in the articles started repeating themselves and there was little new information to gain. Some keywords used in the PubMed search include, but is not limited to, *Ebola, culture, ritual, burial, stigma, funeral and tradition* in different combinations. The study population is mainly the population in the three most affected countries of the 2014-2016 Ebola outbreak; Guinea, Liberia and Sierra Leone. The estimated populations of these countries are approximately, 13 million, 4,9 million and 7,7 million, respectively (28).

Throughout the literature search some inclusion criteria have been used. Only articles written in English were included. Most articles reviewed were conducted in the three most affected countries, Sierra Leone, Guinea and Liberia. Articles whose main focus was not culture, traditions, fear or stigma were excluded. With the exception of two articles, all studies that were not conducted during or after the 2014-2016 Ebola outbreak and revolves around this was excluded. The first exception is a study about the fear and stigma of the

2003 outbreak of SARS. This study was included to be able to compare the relevant outbreak to outbreaks of other diseases, and thereby assess whether the findings of this literature review can be applicable to other serious epidemics. The second exception is a study conducted in Uganda on the cultural contexts of Ebola after the 2001 epidemic. This article was included to make it possible to compare the cultural aspects of the 2001 outbreak to the ones in 2014-2016, in order to see if this might have been one of the reasons the latest outbreak became much bigger than all the previous ones that are known.

Results

Traditional burial practices and the impact of safe and dignified burials

Findings in several studies suggested that rituals related to burials and funerals were one of the most important cultural behaviors for transmission of EVD. The most commonly mentioned risk factors related to these practices were washing the body of the deceased, touching the body as a way of saying their goodbyes and burying the body (29,30,31,32,33). A summary of behaviors like these identified in Ghana can be found in table 2 (29). One study revealed that only 7 % used any kind of protection during exposure to deceased Ebola victims (17). Use of protective equipment was stated to be disrespectful (29). In addition to these common rituals, other, less common rituals were also described. Examples of these were people drinking or bathing in water used to clean the body of the deceased, rituals that are believed to fortify children or to give spiritual protection (29). In some communities, if a man dies, the wife has to shave her head and cover it with mud made from wash water from the corpse, in order to prevent the husbands' soul from getting jealous when she remarries (30). The level of Ebola virus in bodily fluids is highest at the time around death and in the days following, making these rituals extremely high risk (24).

Table 2. High-risk funeral and burial practices in Ghana

Region	Care of the corpse	Funeral practices	Burial practices
Greater Accra	Bathing the dead	Sharing cigarette and drinks with the dead	Holding the body of dead during burial
	Performing ablution	Hand Shaking	Burying deaths that occur at home without autopsy
Western	Bathing the dead	Use of handkerchief to wipe discharges from the dead	Holding the body of dead during burial
	Performing ablution	Widows rites	Burying deaths that occur at home without autopsy
		Drinking water used to rinse the dead	
		Sharing cigarette and drinks with the dead	
		Handshaking	
Volta	Bathing the dead	Use of handkerchief to wipe discharges from the dead	Holding the body of dead during burial
	Performing ablution	Handshaking	Burying deaths that occur at home without autopsy
Ashanti	Bathing the dead	Use of handkerchief to wipe discharges from the dead	Holding the body of dead during burial
	Performing ablution	Handshaking	Burying deaths that occur at home without autopsy
Northern	Bathing the dead	Use of handkerchief to wipe discharges from the dead	Holding the body of dead during burial
	Performing ablution	Throwing money at the dead which get contaminated by discharges from the dead	Burying deaths that occur at home without autopsy
		Handshaking	
		Bathing children with water used to rinse the body of the dead	
		Allowing children to drink the water used to rinse the body of the dead	

One study had the purpose of estimating the number of EVD cases prevented due to safe and dignified burials (SDBs). This study examined 45 unsafe burials, and identified 310 people who had been exposed to the corpse through these burials, resulting in an average of 7 contacts per burial (table 3). 65 % of the people examined reported to have become sick after exposure, but only 25 % were laboratory confirmed cases. 46 % of people had contact with an Ebola victim both before and after death. The baseline estimate (including only infected people who had only been in contact with the deceased after death) showed that 9,5 % of people became sick, while the ceiling estimate (people who became sick who had contact with the deceased both before and after death) gave an estimate of 68 %.

Throughout the Ebola epidemic in 2014-2016, the Red Cross conducted 47 505 SDBs, out of which 2 205 were confirmed EVD cases by laboratory tests. Using the numbers of secondary cases caused by unsafe burials, it was estimated that between 1 411 and 10 452 secondary cases were prevented because of the safe and dignified burial programs, resulting in a total reduction of the outbreak by 4,9-36,5 % (17).

Table 3. Description of reported primary case contacts as described by key informants by country and districts

	Sierra Leone			Guinea		Liberia	Overall
	Western Area Rural	Kambia	Kailahun	Guéckédou	Forécariah	Montserrado	Total
Communities included, N	6	5	9	8	2	12	42
Burials investigated, N	6	5	9	8	3	14	45
Contacts identified, N	46	18	77	69	24	76	310
Contacts per burial, median [range]	8 [2–13]	2 [2–8]	8 [4–19]	11 [3–20]	5 [4–15]	5 [1–12]	7 [1–20]
Age⁺, median [IQR]	54 [20–48]	35 [30–50]	45 [35–55]	40 [33–55]	30 [23–46]	39 [29–55]	40 [30–40]
Sex, % male	50	72	56	75	58	54	60
Health status known, n (% of N contacts identified)	42 (91.3)	15 (83.4)	77 (100)	69 (100)	75 (98.7)	23 (95.9)	301 (97.1)
Sick, n (% of N contacts identified)	41 (89)	6 (33)	29 (38)	50 (72)	14 (58)	63 (83)	203 (65)
Confirmed EVD infection, n (% of N contacts identified)	33 (71)	5 (28)	7 (9)	4 (6)	5 (21)	24 (32)	78 (25)

* All percentages rounded to the nearest whole number; categorical variables will not always sum to 100%

⁺ Age was not reported for 57 individuals in Sierra Leone (Western Area Rural = 22, Kambia = 5 and Kailahun = 30)

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Though all articles who dealt with burial practices agreed that these were a big threat when it came to transmission of the disease, some results were also contradictory. In certain communities the paternal aunts were responsible for preparing the body for the burial, while in other communities the responsible person should be the same sex as the deceased (30,31). Others again found that women were responsible for taking care of the sick, while men dealt with the care of the body after death and the burial rituals (29). During an Ebola

outbreak in Uganda in 2000-2001, it was found that, in a community where women were caregivers and were responsible for burials, 63 % of all EVD cases were women (31). Another aspect that differed between, and within literature, was the willingness of and attitude towards modifying cultural rituals. In a study conducted in Ghana it was found that in most communities cleaning the body after death was mandatory and was not subject to change. This was caused by the fear that the soul of the deceased would haunt them if they did not follow tradition. However, in northern Ghana some people stated that if the death was caused by Ebola, people would not be willing to conduct such high-risk rituals (29).

Caregiving and healthcare seeking behavior

Several reasons were identified for why people cared for sick people at home instead of taking them to healthcare facilities or ETCs. In certain communities it was common practice, even before the EVD outbreak, to self-medicate at home or to use herbs, before seeking help from healthcare professionals or traditional healers. One study described that “*some conditions are not “sickness meant for the hospital”*”, in the sense that these had spiritual or supernatural origin (29). One study revealed that people who took care of the sick at home and were also in contact with the body after death occurred, had 2,63-5,97 times higher chances of becoming infected when compared to people who only had contact with the corpse (17).

In cases where the attempt to treat people at home failed, the next step would be to seek help from a traditional healer (31). This in itself posed new threats of transmission of EVD. People were still out in the community and risked infecting other people, and in case traditional healers were infected they could transmit it onto several of their patients. Some studies indicated that practices conducted by traditional healers were of high risk of transmission. For instance, one traditional healer became infected and continued treating patients. Some people reported that she used a method where she cut people and sucked out the poison that was believed to cause the illness (31). Local authorities in Sierra Leone also estimated that the burial of one traditional healer might have been the cause of 365 secondary deaths (20).

Another common factor that contributed to at home care was the fear of what happened to patients in ETCs. This fear was rooted in the fact that people in the communities had seen sick people going to ETCs and never coming back, without any knowledge of what happened to the person. This resulted in rumours and mistrust (31,33,34). This included ideas that people going to ETCs would get a pill that would kill them or that their organs would be stolen and given to other people (34). A study conducted to examine the different social factors that need to be taken into consideration, found that in communities in Sierra Leone, the level of trust was generally high but lowest in people characterized as “strangers”, people born outside the local community (30). However, studies suggested that people trusted and listen to community leaders and religious leaders (29). Mistrust in strangers contributed to escalated levels of fear of seeking healthcare. People feared that they would never see their families again, and feared the consequences of what would happen if they died and did not get a traditional burial (31,33). Avoiding healthcare facilities and ETCs did not just lead to the risk of transmission through caregiving, but also led to yet another potential unsafe burial. *“From a public health standpoint, EVD deaths should never occur at home”* (33).

Messages conflicting with life and culture

People reported that different public health messages that were meant to prevent further transmission of the disease were contradictory with their everyday lives and their culture. People were advised not to shake hands in different social settings. Shaking hands is seen as a sign of love, and is a common practice in funerals, religious settings and when greeting friends or colleagues. In some cases it is even seen as mandatory. Avoiding it can be considered rude or disrespectful. People were also advised not to eat bush meat, since this is one of the sources of transmission of the Ebola virus. In some villages bush meat is the most important source of protein, and people therefore rely on it in their diet. Women, who are most often caretakers in case someone gets sick, also stated that they would not listen to public health messages telling them not to take care of their families if somebody got sick. One woman said that *“It will be impossible that my child or husband is sick and I refuse to touch them. I do not have the courage or heart to do that”* (32).

Terms	<i>Yat</i>	<i>Gemo</i>	Disease of contact; Ebola
Description	“Medicine” or substance that enters the body and causes illness	Bad spirit that comes suddenly and rapidly and effects many people	EHF, biomedical description
Signs and symptoms	Starts with pain inflammation but can have many other signs in later stages	Mental confusion, rapid death, high fever	High fever, vomiting, headache
Causes	Bad “medicine” (poison) goes into body	Lack of respect for <i>jok</i> , sometimes no reason	Filovirus, but host reservoir unknown
Transmission	Step on it, eat it, catching it, somebody sends, just looking at a person	Physical proximity, easy for <i>gemo</i> to catch you	Physical contact with bodily fluids of patients
Pathophysiology	Inflammation and pain in area touched by or location of <i>yat</i>	Attacks all of body	Damage to major organs
Treatment	<i>Tak</i> —techniques of healers who use their <i>jok</i> to identify and remove <i>yat</i> from body or environment	Talk to <i>jok</i> via traditional healer, give whatever wants, gifts of food to <i>jok</i>	None, hydrate (ORS), control vomiting
Prevention and control	Protective bracelets	See protocol in text, <i>chani labolo</i> , <i>ryemo gemo</i>	Do not touch patients, barrier nursing
Prognosis	Good if removed from body; otherwise death	Not good, no cure	Not good, no cure
Risk groups	Very smart, successful, salaried people; anybody	Caregivers close to patients (women), families that do not respect <i>jok</i> , families that do not follow protocol	Unprotected healthcare workers, caregivers of patients, people that wash or touch dead victims
Political	Infected troops returning from DRC sent to Gulu	Infected troops returning from DRC sent to Gulu	Infected troops returning from DRC sent to Gulu

An example of protective cultural belief

A study conducted after the 2000-2001 Ebola outbreak in Uganda revealed 3 explanatory models (table 4). While one explanation was the biomedical description of Ebola, another was some sort of poison which was believed to be the cause, a third explanation was caused by bad spirits that emerged quickly and caused a lot of illness and death. This was called *gemo*. 98 % of the people who were interviewed in this study said they believed *gemo* was the cause of the epidemic at some point. Because it was believed that *gemo* could be “caught” by healthy people if they came in close contact with the sick, a prevention protocol existed, including isolation of the patient and somehow identifying their house so people would stay away. Though people did not believe there was any treatment for *gemo*, many these protective measures are the same as in cases of Ebola virus disease. If a person had supposedly died from *gemo*, an exception from the traditional burial was made to prevent the participants from catching *gemo*. Even though the three explanatory models have quite different views, people commented that they were not necessarily contradictory; “*Acholi are aware of the biomedical model but view illness as having social, spiritual, and biological dimensions*” (31). There were no such protective cultural practices described in literature from the 2014-2016 outbreak in West Africa.

Table 4. Explanatory models for EVD among the Acholi

Fear and stigmatization

Another common issue that was mentioned was the fear and stigmatization related to EVD. One of the groups that often reported to experience stigmatization was the survivors of EVD. People who had not been infected by EVD were asked how much time would have to pass before they felt comfortable touching a survivor. 49 % said they would feel comfortable being in contact with them one month after they had been declared non-infectious at the hospital. However, survivors reported that they experienced stigma long after this period as well (31). This resulted in trouble reintegrating survivors into their communities again (32). While some were forced to divorce their spouse, others had their houses burned down by the time they came back from ETCs (33). Also the families of infected people and the Ebola burial teams were met with fear, and some were banned from society. When it comes to the victims of Ebola this fear was increased by the cultural perception that the disease was a curse, and that the people affected by it could pass the curse onto others (27).

The stigma experienced by a large proportion of survivors had great repercussions also in other parts of the society. The fear of stigma led to secret burials, migration and avoidance of seeking health care, both for Ebola and non-Ebola health issues (33). The fear of seeking health care arose when people in the communities saw that Ebola victims were taken to treatment centers and never came back. People got suspicious as to what was happening to them and rumours started spreading (23). People rather chose to take care of their loved ones themselves, and sometimes even went to the extreme step of bringing their loved ones into the forest to protect them against what they saw as the enemy; the health care professionals at the Ebola treatment centers (24). According to a study done in Uganda after the 2000-2001 outbreak female survivors were faced with more stigmatization than men (table 5) (31). Also a study conducted after the SARS epidemic in the United States in 2003 found that *“fear associated with stigmatization and discrimination has negatively affected public health efforts with chronic conditions and diseases such as mental illness, HIV/AIDS, tuberculosis, leprosy, and epilepsy”* (26).

Table 5. Ways and locations in which Ebola survivors felt stigmatized

Locations in which survivors felt stigmatized	% of yes responses	
	Men (n=22)	Women (n=38)
Feared by others when you returned to the community	55	82
Rejected at market or store	36	58
Rejected at well or borehole	32	58
Rejected when walking through neighborhood	55	76

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The impact of intervention

Many studies suggested what interventions and changes could be made, but one study focused on the amount and types of activities that were actually implemented in Margibi County in Liberia. From February 2014 to February 2015 95 activities were implemented in the county. Table 6 shows the distribution of activities in categories and gives examples in each category. The study also examined the correlation between number of activities and the incidence of EVD. An increase in the number of activities was seen March 2014 after the outbreak was confirmed by the WHO. After a short while the outbreak was believed to have been eradicated in the county, and no new activities were implemented from April to June 2014. After no new EVD cases for 3 months, a new case was confirmed in late June and the county saw a rapid escalation of cases from there. The number of activities increased along with the EVD cases. After 3 months of strong effort and a high level of implemented activities, the desired wish of a decrease in EVD cases was seen (19).

Table 6. Types of activities implemented in Margibi county, Liberia, the distribution of these and examples.

Category	Number of activities (%)	Examples
Changes at community/system level	46 (48,4)	Implementing policies, sanitation initiatives
Development activities	33 (34,7)	Meetings with religious/traditional leaders, collaboration between partner organizations
Services provided	11 (11,6)	Hygiene supplies, SDBs
Resources generated	5 (5,3)	Funding, gifts-in-kind resources

Discussion

When one case leads to 28 000

This literature study aims to reflect the complexity of cultural factors that need to be addressed in the case of a new comprehensive Ebola epidemic. The 2014-2016 Ebola outbreak started when a young boy was infected by the virus through contact with a bush animal. No other case in this outbreak is believed to be caused by animal to human transmission, which means every single case has its origin in the same index case (33). When one case resulted in a total of more than 28 000 infected people, it is necessary to take a look at the human interactions that complicated and escalated the outbreak to such a scale. It is also important to understand the factors that contributed to the biggest known Ebola outbreak since its discovery in 1976, in order to prevent the same thing from happening again.

Burials, funeral rituals and the significance of SDBs

When you are examining cultural factors in a context like this, it is natural to take a particularly close look at burials and funeral rituals. In any culture, rituals related to birth and death play a big role in people's lives, and can therefore be challenging to change. All studies that dealt with funeral rituals saw this as a tradition with high risk of transmission. One study estimated the average number of secondary cases related to burial rituals to be 2,58. Many different aspects of funeral and burial rituals were highlighted as common and concerning rituals, and the risk of infection at this stage is high due to the high levels of virus in the bodily fluids after death. As anticipated, direct contact with blood or bodily fluids was the type of contact of highest risk (17). In a purely biomedical perspective, it makes no sense that people expose themselves to a dead body when the risk of transmission is known to be high. It is therefore utterly important to understand why some people still continued this high risk behavior. Understanding the reasons behind it is the only way efficient and useful interventions can be proposed and put into action.

Throughout the Ebola epidemic in 2014-2016, the Red Cross conducted 47 505 SDBs in Sierra Leone, Liberia and Guinea. The program was initiated at different stages of the epidemic in the different countries and the impact therefore varied. If SDBs are initiated when the prevalence of disease is high, the impact would be higher, because a higher percentage of the burials would be Ebola positive cases, whereas the impact would be lower when the prevalence is low, because most of the people buried would have died of some other disease (17). It is still important to emphasize that in times when the prevalence of the disease is low, e.g. in the beginning and at the end of an epidemic, it is still crucial to continue SDBs, in order to kill the epidemic at its root or get it under control once and for all, respectively. The sooner such a program is put into place, the better. This way, the disease can be prevented from spreading further and the amount of resources needed would be manageable (29). A study conducted by A. Tiffany et.al. found that the number of secondary cases prevented by the Red Cross SDB programs lies somewhere between 1 411 and 10 452. Had it not been for these programs, the total number of EVD cases could have been 30 012 to 39 053. However, this study does not account for the chain of transmission that all these secondary cases could have led to. The total number of EVD cases could therefore have been even higher than the number estimated here, had it not been for the SDB programs (17).

Is there a way to avoid at home caregiving?

One of the aspects of the West African culture that has been proven difficult to adjust is the care people give to their family members or loved ones at home in case they get sick. People said it would be impossible to avoid caring for their close ones because of the risk of transmission of a disease (34,32). This problem escalated because of the fact that people feared what would happen if they went to the ETCs, both because of rumours and stigma, and therefore chose to stay at home instead (26,34). This is an important area to target in the future, as caregiving is a huge risk of transmission (17). In order to avoid this, the health care offered needs to be accessible, available and of high enough quality. Imagine yourself, if one of your family members fell sick and there was no health care facility to take care of them, would you leave them alone to die?

In order to avoid this, communities tried to figure out how to provide people with the tools and knowledge to handle sick people or deceased in their communities in case it took time for the ambulances or burial teams to reach. The resources were limited and the demand high. The information on how to handle such situations should include both advice on how to care for the sick and also how to handle the body in case death occurs, and it should be taken into consideration that the access to equipment can be limited. A study conducted in rural Sierra Leone suggested a quite detailed way of doing this, and it goes as follows. Only one person should be the care giver of the sick. The use of oral rehydration salts(ORS) should be introduced as soon as possible. Burials should be carried out only by professional burial teams, and in case washing of the corpse cannot be avoided, appropriate protection should be used (30). This solution limits the number of contacts with infected people, and gives people some basic guidelines on how to deal with challenging situations like this. This can be extremely important, especially in rural settings where resources may be limited and the much needed help can be far away.

Community resistance and communication of public health messages

Challenges in communication exist in all settings, but might become more distinct in situations where there is also a conflict in culture. Many public health messages conflicted with the life and culture of people in the communities, and this complicated things further. Without fully understanding the background and reasons behind different cultural rituals and traditions, it is challenging to give advice that does not conflict with them. One of the studies reviewed, put it this way *“Many national and international healthcare workers tend to view cultural practices and beliefs as something to overcome[...]*” (31). This was mentioned as a problem by several survivors of EVD. It was also pointed out that if it comes to a choice between culture and knowledge based advice, culture would be prioritized. In future epidemics, it will therefore be important to collaborate with essential leaders in the communities and together make a communication plan that takes culture into consideration and is concise throughout the outbreak. As stated in one study, *“[...] messages should be formulated in an effort to work with culture, rather than against it”* (34,30). Another study suggested that it would be easier to change people’s behavior if the public health messages

were communicated through community leaders, as the level of trust is higher in them than in people from the outside (29).

There were variations between countries and between cultures in the willingness to change these traditions (29). The reason why some people were less willing than others to change their rituals were not described in detail, but probably has several sides. The mistrust in “strangers” was mentioned as one possible reason, as was the confusion around public health messages. Several of the most affected countries have a recent history of civil wars and conflict, and this had an impact on the compliance of public health messages, especially when it was delivered by people who came into the society from the outside (34).

Collaboration with community leaders would be an important step in the right direction in getting people to listen to the public health messages and trust the content of them. On the other side, in some areas people were more willing to change their practices if they were able to see the most practical solution, like for example the fact that it would make more sense to bury an infected body at the place that death occurred instead of bringing it home to the village for burial (30). Also, if the cause of disease, routes of transmission and the connection between rituals and the potential of transmission is carefully explained to people in a way that make them understand the risks, this could be an effective way of making them more willing to change their behavior (30).

Understanding is the key to change

An important aspect to understand is the background of the traditions and rituals. As described in the results part of this thesis, many people saw it as mandatory to continue their burial rituals and other traditions, even when they knew the risks associated with it. Several reasons for this were mentioned. One explanation was the fear of what would happen to the ones left behind or to the soul of the deceased if they did not go through with the rituals. Abstaining important rituals could result in haunting of the family or the whole village, by the soul of the deceased. Another reason to ignore public health messages was the lack of respect it would show the deceased if they deviated from the normal customs (29). A custom not related to burials that were also advised against during the outbreak was

greeting people with a handshake. It would be considered rude if you did not shake peoples hand in different scenarios (34). As you can see, all customs and rituals have an explanation, and for the people involved the consequences of abstaining cultural rituals were considered worse than the possibility of contracting a disease.

One commonly suggested solution was to find an alternative way for people to practice their rituals and cultural norms, in a way that did not put them at risk for transmission. In order to limit the contact between people, one study suggested replacing the regular handshake as a way of greeting people with a fist bump or a high five (29). An important tradition in some cultures is for the family to keep belongings of the deceased. A way of preserving this tradition could be to disinfect certain belongings before handing it over to the family, as a compromise (35). In the absence of alternatives, people will stick to their old rituals, and it will be important to suggest alternatives, not just in the situations mentioned above, but when it comes to all high risk behavior (29). In situations where rituals and traditions are mandatory and there are no acceptable alternatives for the people, protection is highly recommended (30).

In the results part of this thesis a protective approach to traditions related to illness and death was presented. These findings were described in a study conducted in Uganda during the 2000-2001 epidemic, and shows an ethnic group where the interventions done after a suspected disease breaks out is quite similar to the ones you would hope for in an Ebola outbreak (31). Though the mindset of it is different, the behavior it leads to might have had a great preventable impact. There are no such preventive adaptations in rituals or traditions described in the literature of the 2014-2016 outbreak. Perhaps one can learn from the Acholi ethnic group of Uganda in case of a new epidemic, by talking to religious and community leaders and figure out if there is potential in changing these kinds of beliefs into something that can protect its people. It was mentioned that the public health education program introduced in this community met little resistance, exactly due to the fact that the suggested control measures that the government wanted to implement was in line with the protective measures they themselves implemented because of their beliefs.

In addition to the ones mentioned above, several other interventions and adjustments have been suggested in the literature. Survivors of EVD in Sierra Leone and Liberia expressed a desire for the ETCs to be situated closer to the people. They had experienced that the distance between the people and the ETCs took part in increasing the fear and stigma related to the disease, as well as maintaining the rumours and misconceptions of the disease and what happened at the ETCs (34). This should also include letting people see their loved ones after they have passed away, as refusing this may also be a source of rumours in the communities (31). As mentioned previously, people would try self-medicating at home before seeking any professional help. The result of this is that it is not the health care professionals who are the first people to meet victims of Ebola, it is the people working in the drug stores. It could therefore be an idea to teach these how to screen people for EVD in order to detect infected people and thereby prevent community transmission at an early stage (29). Even though a lot of interventions have been suggested and it was found that an increase in the amount of activities implemented was associated with a decrease in the number of EVD cases, it is difficult to measure which activities have an impact and which do not (19).

Culture can not be the only explanation for the high prevalence

Another important line to draw from literature from the 2000-2001 outbreak, is the fact that, even though protective culture was found in one ethnic group, risky cultural behavior was also described (31). This suggests that cultural factors also played a role in 2000-2001, just like it did it in the 2014-2016 outbreak. However, this also means that culture cannot have been the sole reason why the 2014-2016 outbreak became so much bigger and more widespread than previous ones. Some suggest that a contributing reason to this is the fact that Ebola is not commonly seen in West Africa. People were therefore not aware of the signs and symptoms, the routes of transmission and the risk of human interactions, and the communities were not prepared for such a disease. Several other factors may also have contributed to the great extent of this outbreak, but these need to be examined closer to better understand and better prepare for a new outbreak.

Fear and stigmatization in different contexts

When it comes to the fear and stigma that occur in extreme situations like an Ebola epidemic, it is safe to say that this is a big issue and can complicate the situation further. This was also examined after a SARS epidemic in the US in 2003. Fear is associated with a lower compliance of public health messages, both when it comes to infectious diseases and chronic diseases. People avoid seeking health care for several reasons, including fear of contracting the disease, fear of treatment centers and the fear of the stigma that could be a result of being labeled an Ebola patient (34). It is therefore necessary that we see the disease that we are dealing with “[...] in a medical, social, and cultural context” (26). There are similarities between the findings after the SARS epidemic in the US and after the Ebola epidemic in West Africa which could suggest that the findings of this thesis can be applicable to other diseases of similar character.

Learning from the success of Nigeria and Senegal

Lastly, we need to take a look at the success factors of the outbreak management in Nigeria and Senegal. Because of their quick and broad response, Senegal only had one confirmed case and Nigeria 19 (36). Some key components included early suspicion of EVD, isolation of all suspected cases and close monitoring of all contacts of infected people. In Nigeria 18 500 houses were visited to track down contacts of infected people. Out of these, 894 were identified as contacts and were monitored until disease could be ruled out. They also set up a cell phone text message system for reporting and health care workers visited everybody who reported symptoms of Ebola. To make sure the people who were being monitored in Senegal cooperated, they were offered food, money and psychological counselling in return. Senegal set down a National Crisis Committee already in March 2014. When the first case was reported in August the same year, they knew exactly how to handle it (37). Some of these factors coincide with the data presented in this literature review. A rapid and systematic response is the key in preventing an escalation of these kinds of outbreaks. Although very effective, in some situations it can be easier said than done. These are strategies that require a certain level of infrastructure and a large amount of resources. However, the consequences of abstaining can be dramatic. As put by the WHO: *“The most important lesson for the world at large is this: An immediate, broad-based and well-co-*

ordinated response can stop the Ebola virus... dead in its tracks” (37). Although this thesis aims to find a way for cultural rituals and safety to coexist, in extreme situations it might still be necessary to do what you have to in order to save lives.

Limitations

When conducting a literature study it can be challenging to stay 100 % neutral, and this thesis is no exception. For example certain relevant literature may have been excluded during the literature search based on the fact that the results did not match the planned perspective of the thesis. No articles are included in this study that showed that culture did not play a role in the outbreak. Is this because this is the reality and there is no literature describing such findings, are these kinds of findings simply not published for various reasons or are they excluded from this study because they did not fit in? Another possible weakness of this thesis is that it solely depends on existing research. The opportunity to make new findings or chose your own point of view is simply not there, because we were dependent on using existing literature. Although this might be a weakness, this also allows for a summarization of existing literature, which may give some system in the chaos of published research. The existing data on this topic is limited, and the diversity and quality of the studies used in this literature study reflects that.

Conclusion

Several cultural factors have played a role in making the 2014-2016 Ebola epidemic the biggest one that is known so far. Some of the most common cultural factors to have had an impact on the size of the outbreak are burials and funeral rituals and caregiving at home. Factors like fear, stigmatization, mistrust and challenges in communication are also mentioned as contributing factors. It is important to understand the background of cultural rituals to understand why they are not always subject to change. Fear and stigmatization has played a role, as this has made people avoid health care facilities and thereby increased the risk of transmission in the communities. Interventions do have an impact, but need to be conducted in the right way and for the right purpose; otherwise it may act against its intention.

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Attachment 1

<p>Reference: Tiffany A, Dalziel BD, Kagume Njenge H, Johnson G, Nugba Ballah R, James D, et al. (2017) Estimating the number of secondary Ebola cases resulting from an unsafe burial and risk factors for transmission during the West Africa Ebola epidemic. PLoS Negl Trop Dis 11 (6): e0005491.</p>			<p>Design: Retrospective cohort</p>
			<p>Quality of evidence Ila</p>
			<p>Strength of recommendation A</p>
Purpose	Material/methods	Results	Discussion/comments
<p>Estimate number of secondary cases of Ebola virus disease(EVD) averted by safe and dignified burials(SDB).</p> <p>Describe risk factors for EVD transmission during unsafe burials.</p>	<p>Data was collected from June to August 2015, by epidemiologists doing interviews in six different districts, three in Sierra Leone, two in Guinea and one in Liberia. Key informants were identified by the local Red Cross. As far as it was doable, one key informant was selected to give information on a specific burial.</p> <p>The districts were randomly selected based on some sampling frame criteria. They were all districts where the Red Cross were responsible for conducting SDB. At least one of the following criteria had to be met: 1) Cases of Ebola 2) Community deaths during the period of the epidemic 3) Having a community member hospitalized in an Ebola Treatment Center(ETC)</p> <p>One group of 10 communities, that met these criteria were randomly selected. It was then identified whether these communities had any cases of EVD and if an unsafe burial of an EVD case had happened. Communities that were exposed to both of these were included in the study.</p> <p>A standardized questionnaire was used to collect information from key informants regarding the primary case; age, sex, source of infection, EVD swab confirmation and secondary cases in contacts. Data was also collected for each of these contacts; age, sex, type of contact, current status(alive/dead) and EVD swab confirmation.</p> <p>Two datasets were used; the first using data from EVD cases where contact only happened after death, the second included cases where contacted were made both before and after death. To estimate the number of cases averted by SDB, the average number of potential secondary cases per unsafe burial multiplied by the number of EVD positive SDB conducted by the Red Cross.</p>	<p>45 unsafe burials in 42 different districts were analyzed. 2 of these reported no secondary cases. In total 310 people had been in contact with the body of a EVD case after death. This gives an average of 7 contacts per unsafe burial. 65 % of contacts resulted in a secondary case. However this varied from 33 % to 89 % in the different districts. 41 % of all secondary cases only had contact with the primary case after death. The key informants did not have all information required in all cases, and after adjusting for those whose health status was known, 25 % of contacts got sick and had a positive swab test.</p> <p>Types of contact were divided into seven categories. 46 % had been in contact with the EVD case both before and after death. Only 7 % of all contacts had used some sort of protection when in contact with the sick or dead. The highest risk of being contaminated was related to contact with body fluids of the sick/dead or being in direct physical contact with them.</p> <p>9,5 % of people exposed to a EVD case after its death became secondary cases. An even higher risk of becoming a secondary case was seen in cases where contact happened both before and after the death of the primary case, this was calculated to 68 %. The risk of being infected when contact with the primary case happened both before and after death was 2,63 to 5,97 times more likely than when contact only happened after death.</p> <p>In total 47 505 people were buried by the Red Cross, using a SDB. A laboratory test were taken of all these, and 2 205 (4,6 %) of these came back positive for Ebola. This number was used to estimate the number of secondary cases averted by conducting SDBs by the Red Cross. This was done by multiplying the number of SDBs with average contacts per unsafe burial and thereafter multiplying with the percentage of contacts that resulted in secondary cases. The estimated prevented cases were between 1 411 and 10 452. Using these numbers, it can be calculated that SDBs reduced the number of people affect during the epidemic between 4,9 % and 36,5 %.</p>	<p>Checklist:</p> <p>Is the purpose of the study clearly formulated? Yes</p> <p>Is the method appropriate to give answers to the purpose? Yes</p> <p>Is the layout of the study appropriate to give answers the purpose? Yes</p> <p>Is the selection strategy appropriate to give answers to the purpose? Yes</p> <p>Were the data collected in a way that the purpose was answered? Yes</p> <p>Was background information that may have impacted the evaluation of data explained? Yes</p> <p>Are ethical conditions considered? Yes</p> <p>Is it clear how the analysis has been conducted? Yes</p> <p>Are the findings clearly presented? Yes</p> <p>Weaknesses</p> <ul style="list-style-type: none"> - Recall bias - Information was not always collected from the person itself - Closest informants were not always available due to death or hospitalization <p>Strengths</p> <ul style="list-style-type: none"> - There are no other studies examining this
Conclusion			
<p>SDBs prevented an estimate between 1 411 and 10 452 secondary cases of Ebola virus disease. Between 9,5 % and 68 % of people who were in contact with a primary case before and/or after death became infected. The risk of being infected were between 2,63 to 5,97 times higher when contact happened both before and after death. Contact with body fluids and direct physical contact with the primary case increased the risk of becoming infected.</p>			
Country			
Sierra Leone, Guinea, Liberia			
Year of data collection			
2015			

Attachment 2

Reference: Sepers C E, Fawcett S B, Hassaballa I, DiGennaro Reed F, Schultz J, Munodawafa D et.al. Evaluating implementation of the Ebola response in Margibi County, Liberia. Health Promotion International. 2018; 1-9. https://doi.org/10.1093/heapro/day010			Design: Case study
			Quality of evidence III
			Strength of recommendation D
Purpose	Material/methods	Results	Discussion/comments
<p>The study aimed to answer the following two questions:</p> <p>1. <i>“What amount and kind of Ebola response activities were implemented in Margibi County, Liberia?”</i></p> <p>2. <i>“What factors corresponded with increased levels of implementation and reduction of EVD incidence in Margibi County, Liberia?”</i></p>	<p>The study was a collaboration between the World Health Organization Regional Office of Africa (WHO AFRO) and the Work Group for Community Health and Development (WHO Collaborating Center). A Monitoring and Evaluation (M&E) system was used to examine what kind of activities were implemented by the WHO in the response against Ebola and the number of such activities.</p> <p>Activities were categorized within five categories:</p> <ol style="list-style-type: none"> 1. Surveillance, contact tracing and case investigation 2. Case management 3. Safe burials 4. Social mobilization and community engagement 5. Delivery of basic services <p>Data was collected through interviews with key informants in Margibi County, Liberia. These 10 key informants reported all Ebola response activities.</p> <p>In addition a systematic document review was done, and each activity was described and coded using a M&E system.</p>	<p><u>What amount and kind of Ebola response activities were implemented in Margibi County, Liberia?</u></p> <p>Interviews with key informants concluded with a total of 95 activities implemented. 48,4 % of these activities were new or modified programs, policies or practices on community or system level. The second biggest group of activities implemented were development activities (34,7 %). The remaining 16,8 % of activities consisted of services provided and resources generated.</p> <p>The document review found a total of 95 activities implemented. The results showed the following distribution of activities:</p> <ul style="list-style-type: none"> - Basic service activities: 12,6 % - Case management: 8,4 % - Contact tracing and surveillance: 15,8 % - Safe and respectful burials: 6,3 % - Social mobilization: 42,1 % - Not characterized/other: 14,7 % <p><u>What factors corresponded with increased levels of implementation and reduction of EVD incidence in Margibi County, Liberia?</u></p> <p>After the confirmation of EVD cases in the area there was a considerable increase in the number of activities implemented. Another increase was seen after the outbreak was concluded by the government. As the number of activities implemented against the outbreak increased, the numbers of EVD cases were decreasing. A new increase in the number of cases was seen in June 2014, followed by another increase in activities, which after 3 months showed an effect on the number of EVD cases.</p>	<p>Checklist:</p> <p>Is the purpose of the study clearly formulated? Yes</p> <p>Is the method appropriate to give answers to the purpose? Yes</p> <p>Is the layout of the study appropriate to give answers the purpose? No</p> <p>Is the selection strategy appropriate to give answers to the purpose? Yes</p> <p>Were the data collected in a way that the purpose was answered? No</p> <p>Was background information that may have impacted the evaluation of data explained? Yes</p> <p>Are ethical conditions considered? No</p> <p>Is it clear how the analysis has been conducted? Yes</p> <p>Are the findings clearly presented? Yes</p> <p>Weaknesses</p> <ul style="list-style-type: none"> - Challenging to collect data retrospectively, list of activities therefore most likely not including all activities <p>Strengths</p> <ul style="list-style-type: none"> - Provides the best understanding of Ebola response activities in this area
Conclusion	<p>A total of 95 activities were implemented in the area, with a wide variety in the type of activities, ranging from changes in community policies to interventions at individual level.</p> <p>Data showed a significant effect of an increase in number of activities on the number of EVD cases.</p>		
Country	Liberia		
Year of data collection	2014-2015		

Attachment 3

Reference: Person B, Sy F, Holton K, et al. Fear and Stigma: The Epidemic within the SARS Outbreak. Emerging Infectious Diseases. 2004;10(2):358-363. doi:10.3201/eid1002.030750.			Design: Case study	
			Quality of evidence	III
			Strength of recommendation	D
Purpose	Material/methodes	Results	Discussion/comments	
<p>To outline efforts to rapidly assess, monitor, and address fears associated with the 2003 severe acute respiratory syndrome(SARS) epidemic in the United States.</p>	<p>Assessments and monitoring were conducted by a Community Outreach Team from the National Center for Infectious Diseases(NCID) at the Center for Disease Control and Prevention(CDC). The team worked on implementation of public health interventions specific to problems associated with fear, stigmatization and discrimination caused by the SARS epidemic.</p>	<p><u>Rapid Situational Assessment</u> The Rapid Situational Assessment was used to develop an intervention strategy. This strategy included collaboration and sharing of information with other SARS emergency response teams, development of culturally customized health education materials and different ways of reaching out to the community to change negative behavior and attitudes.</p>	<p>Checklist:</p> <p>Is the purpose of the study clearly formulated? Yes</p> <p>Is the method appropriate to give answers to the purpose? Yes</p> <p>Is the layout of the study appropriate to give answers the purpose? Yes</p> <p>Is the selection strategy appropriate to give answers to the purpose? Yes</p> <p>Were the data collected in a way that the purpose was answered? Yes</p> <p>Was background information that may have impacted the evaluation of data explained? No</p> <p>Are ethical conditions considered? No</p> <p>Is it clear how the analysis has been conducted? No</p> <p>Are the findings clearly presented? Yes</p> <p>Weaknesses None mentioned</p> <p>Strengths None mentioned</p>	
<p>Conclusion</p> <p>There is a clear connection between public health messages and interventions and the way it affects stigmatization and fear among certain groups in society. This needs to be addressed when societies prepare for the next disease outbreak to prevent stigmatization fear and discrimination, as to prevent another epidemic within an outbreak.</p>	<p>The team targeted groups at particularly high risk of fear, discrimination and stigmatization within the outbreak, e.g. Asian-Americans. Results from monitoring and assessing these groups were used to customize interventions based on needs.</p>	<p><u>Targeted Health Education Materials</u> This was basically an attempt to prioritize and translate existing information and advice to make sure it reached the target group. The information was made available at print and web, and translated into several different, common Asian languages. In addition they created brief, recorded educational hotline messages giving information about risks of illness and death and about preventive measures.</p>		
	<p>A Rapid Situational Assessment was conducted to evaluate the impact of fear, discrimination and stigmatization caused by SARS within the Asian-American society in the US. This included methods like group discussions, CDC Public Response Service data and collection of relevant information sources, among others.</p>	<p><u>Community Field Visits</u> Through Community Field Visits, the team had two main targets; collect information and respond to community needs. They visited Asian communities in several different cities in the US. This way they were able to provide updated, evidence based information about the disease through conversation and presentation, and to break down misconceptions, myths and rumors. Through conversations and discussions with people in the Asian communities the team found that stigmatization was more common within the communities themselves, rather than from the outside in.</p>		
<p>Country</p> <p>The United States of America</p>				
<p>Year of data collection</p> <p>2003</p>	<p>The materials collected throughout this work were collected in an article, to be used to be better prepared to deal with similar issues at the next epidemic.</p>			

Attachment 4

<p>Reference: Schwerdtle P, De Clerck V, Plummer V. Survivors' perceptions of public health messages during an Ebola crisis in Liberia and Sierra Leone: An exploratory study. Nurs Health Sci. 2017;1-6. https://doi.org/10.1111/nhs.12372</p>			<p>Design: Exploratory study</p>				
			<table border="1"> <tr> <td>Quality of evidence</td> <td>IV</td> </tr> <tr> <td>Strength of recommendation</td> <td>B</td> </tr> </table>	Quality of evidence	IV	Strength of recommendation	B
Quality of evidence	IV						
Strength of recommendation	B						
Purpose	Material/methods	Results	Discussion/comments				
<p>The study was conducted to get a broad understanding of Ebola survivors view on the communication related to the Ebola outbreak in West Africa in 2014.</p>	<p>Data was collected as part of a larger survey done by MSF. There were held group interviews in 3 different groups; two in the Bo district in Sierra Leone and one in the city of Monrovia In Liberia. 25 people participated in total. These were recruited by MSF staff, based on four inclusion criteria:</p> <ol style="list-style-type: none"> 1. Age =18 2. Had contracted Ebola, became sick and survived between March 2014 and March 2015 3. Were treated in an ETC 4. Willing to provide a voluntary account of their experiences <p>After advice from locals, the data collection was done using group interviews over individual interviews, as this was more culturally appropriate. Confidentiality was guaranteed.</p>	<p>Theme 1: Degrees of mistrust From the interviews it was found that the degree of mistrust ranged from low to high level of suspicion. It was described that rumours and assumptions influenced the seeking of health care in a negative way. This might also have been affected by the history of colonialism in the region, and the way things were organized during the outbreak.</p> <p>Theme 2: Messages conflicting with life and culture In general messages concerning what to do and not to do were not adapted to the circumstances of the society. One community for example was discouraged to eat bush meat cause of the risk of transmission, while this community was dependent on bush meat to have enough food. Some of these conflicting messages created more fear, but did not necessarily affect the practice. Another message conflicting strongly with the West African culture was the advice not to care for the ill, as this would increase the risk of transmission.</p> <p>Theme 3: Seeing is believing Some communities had difficulties believing the existence of a disease that had never been present in that region before. Some people didn't believe it until they saw it with their own eyes. One suggestion to combat this was to make a closer connection between the ETCs and the communities.</p> <p>Theme 4: Recovery inspires hope As people saw that you could actually recover from this disease, the mistrust in the health care system and personnel sunk. Listening to survivors who came from the ETCs made people hopeful, and increased the trust in the system.</p>	<p>Checklist:</p> <p>Is the purpose of the study clearly formulated? Yes</p> <p>Is the method appropriate to give answers to the purpose? Yes</p> <p>Is the layout of the study appropriate to give answers the purpose? No</p> <p>Is the selection strategy appropriate to give answers to the purpose? Yes</p> <p>Were the data collected in a way that the purpose was answered? Yes</p> <p>Was background information that may have impacted the evaluation of data explained? Yes</p> <p>Are ethical conditions considered? Yes</p> <p>Is it clear how the analysis has been conducted? Yes</p> <p>Are the findings clearly presented? Yes</p> <p>Weaknesses</p> <ul style="list-style-type: none"> - Participants may have influenced each other within the groups - Anonymity was not possible during groups interviews <p>Strengths None mentioned</p>				
Conclusion	<p>It was suggested that in case of a similar outbreak, a communication plan should be established, based on an understanding of the community and its values. There is a wish for stronger focus on the principle of do no harm.</p>						
Country	<p>Sierra Leone and Liberia</p>						
Year of data collection	<p>2015</p>						

Attachment 5

<p>Reference: Adongo PB, Tabong PT-N, Asampong E, Ansong J, Robalo M, Adanu RM (2016) Preparing towards Preventing and Containing an Ebola Virus Disease Outbreak: What Socio-cultural Practices May Affect Containment Efforts in Ghana? PLoS Negl Trop Dis 10(7): e0004852. https://doi.org/10.1371/journal.pntd.0004852</p>			<p>Design: Phenomenological study</p>	
			Quality of evidence	IV
			Strength of recommendation	A
Purpose	Material/methods	Results	Discussion/comments	
<p>Identify socio-cultural factors that can possibly contribute to the spread of Ebola virus disease (EVD).</p> <p>There were no cases of confirmed EVD in Ghana during the 2014-2016 outbreak, but this study was conducted to find possible areas of interventions in case of an Ebola outbreak.</p>	<p>5 out of 10 regions in Ghana were chosen for this study. These were chosen based on population density, rural-urban factors and exit points.</p> <p>5 groups were made in each of the 5 regions, and these groups participated in focus group discussions (FGDs). Each group consisted of 8-10 people. In each region two groups consisted of males, two of females and one of nurses. A total of 235 people participated in the study. Several different questions were asked, and all participants got the chance to answer. The discussions lasted 60-90 minutes.</p> <p>Also, 40 in-depth interviews (IDIs) were conducted. These were mainly community leaders. Discussions and interviews were conducted based on semi-structured guides.</p> <p>Data was analyzed in a qualitative data analysis, using the following steps: familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation.</p>	<p><u>Funeral practices</u></p> <p>Three subgroups were identified; care of the body of the deceased, burial practices and funeral practices. High-risk behavior was found within all three groups, including, but not limited to, bathing the body, performing ablution, touching the body, drinking water used to rinse the deceased and bathing in rinse water. Care of the body of the deceased is often done without protection. Use of protection shows lack of respect. In general, these practices are part of people's culture or religion. In some regions the participants thought people would be willing to change them if the death of the person was thought to be caused by EVD, however in other regions these practices are not possible to change or overlook.</p> <p><u>Daily praxis and practices</u></p> <ul style="list-style-type: none"> - Handshaking was one of the social norms that were highlighted in this study. This is seen as mandatory in a lot of settings. - Sharing drinking glasses would be a way of transmission through saliva, and is done both in bars and in religious settings - Taking care of the sick at home. This is usually a job for the women, which gives them a higher risk of transmission. The men are often responsible for care of the body after death. <p><u>Health care seeking</u></p> <p>A lot of people stated that during the first days of disease, the ill is taken care of at home and the first places they seek help are pharmacies or traditional healers, rather than hospitals. If they are still sick after a few days, they would go to the hospital to get help. Some also pointed out that some conditions are caused by spiritual or supernatural things, and there's therefore no point going to the hospital when this happens.</p> <p><u>Influence of socio-cultural barriers to prevention</u></p> <p>The participants in the study were generally of the opinion that community and religious leaders had the trust and power to make people change their behavior if they saw it necessary because of a disease like EVD.</p>	<p>Checklist:</p> <p>Is the purpose of the study clearly formulated? Yes</p> <p>Is the method appropriate to give answers to the purpose? Yes</p> <p>Is the layout of the study appropriate to give answers the purpose? Yes</p> <p>Is the selection strategy appropriate to give answers to the purpose? Yes</p> <p>Were the data collected in a way that the purpose was answered? Yes</p> <p>Was background information that may have impacted the evaluation of data explained? Yes</p> <p>Are ethical conditions considered? Yes</p> <p>Is it clear how the analysis has been conducted? Yes</p> <p>Are the findings clearly presented? Yes</p> <p>Weaknesses</p> <ul style="list-style-type: none"> - Loss of meaning due to translation - The study was only conducted in 5/10 regions in Ghana <p>Strengths</p> <p>None mentioned</p>	
Conclusion				
The study was able to find several high-risk socio-cultural practices and behaviors in the society. These may increase transmission of a possible EVD outbreak. In this case community leaders should be approached to help change these behaviors.				
Country				
Ghana				
Year of data collection				
2015				

Attachment 6

Reference: Richards P, Amara J, Ferme MC, Kamara P, Mokuwa E, Sheriff AI, et al. (2015) Social Pathways for Ebola Virus Disease in Rural Sierra Leone, and Some Implications for Containment. PLoS Negl Trop Dis 9(4): e0003567. doi:10.1371/journal.pntd.0003567		Design: Case study	
		Quality of evidence	III
		Strength of recommendation	D
Purpose	Material/methods	Results	Discussion/comments
What social factors need to be considered and addressed to control an Ebola epidemic?	A national survey was conducted in the rural areas of Sierra Leone, through multiple rounds of detailed surveys. The intention was to assess levels of rural institutional change in the post-civil war period. Four parts of this survey was used in this study: 1) Household structures and food security in tree isolated communities in northern Moyamba District 2) A national random sample of 2200 rural households in 117 villages 3) A survey of 91 villages around the Gola Rainforest National Park in Kenema, Kailahun and Pujehun districts 4) A survey of 187 village communities and 2460 households	<u>Trust</u> The general level of trust is high, but is highest in other household members and extended family. There's a low level of trust in people who are not originally from the local community. People therefore tend to stick to their close ones in challenging situations, such as illness. <u>Marriage and funerals</u> Funerals and burials are a major risk for Ebola transmission, because of touching, washing and caring for the dead without any protection. In some communities were one part of the married couple is from a different village than the other, the deceased may have to be taken back to their origins. This poses a threat of transmission of Ebola. <u>Migration</u> Migration between villages happen for different reason, including trade and marriage. This can help Ebola spread to new communities that have not yet been affected by the outbreak.	Checklist: Is the purpose of the study clearly formulated? No Is the method appropriate to give answers to the purpose? No Is the layout of the study appropriate to give answers to the purpose? No Is the selection strategy appropriate to give answers to the purpose? Yes Were the data collected in a way that the purpose was answered? Yes Was background information that may have impacted the evaluation of data explained? No Are ethical conditions considered? No Is it clear how the analysis has been conducted? No Are the findings clearly presented? No Weaknesses None mentioned Strengths None mentioned
Conclusion			
Social factors need to be taken into consideration when dealing with an Ebola outbreak, and it is important for the control of the outbreak that these are understood, including the challenges faced with rural-urban extended family network.			
Country			
Sierra Leone			
Year of data collection			
2011-2014			

Attachment 7

<p>Reference: Hewlett BS, Amola RP. Cultural Contexts of Ebola in Northern Uganda. Emerging Infectious Diseases. 2003 Oct; 9(10):1242-8.</p>			<p>Design: Cohort/phenomenological study</p>				
			<table border="1"> <tr> <td>Quality of evidence</td> <td>Ila/IV</td> </tr> <tr> <td>Strength of recommendation</td> <td>C</td> </tr> </table>	Quality of evidence	Ila/IV	Strength of recommendation	C
Quality of evidence	Ila/IV						
Strength of recommendation	C						
Purpose	Material/methods	Results	Discussion/comments				
<p>This study had 3 aims:</p> <p>1) Describe local explanatory models of Ebola Virus Disease(EVD)</p> <p>2) Give an understanding of cultural factors of concern to the WHO</p> <p>3) Identify local and international beliefs and behaviors that complicates prevention of EVD transmission</p>	<p>Both qualitative and quantitative methods were used in this study. This included interviews, focus group discussions, questionnaires and document reviews.</p> <p><u>Interviews and focus groups</u> Different groups in society was targeted: 1) 10 persons and 4 focus groups in villages with large numbers of early cases of EVD 2) 8 persons and 1 focus group with survivors of EVD 3) 4 focus groups with elders 4) 3 persons and 2 focus groups of children 5) 4 persons and 2 focus groups with healthcare workers 6) 4 persons and 1 focus group with traditional healers</p> <p><u>Questionnaires</u> These were handed out to 85 High School students and 49 adults in Gulu.</p> <p><u>Document review</u> Existing literature, such as field reports and health education materials were examined.</p>	<p><u>Explanatory models</u> Following the debut of the outbreak, three explanatory models were used. During the early stages of the outbreak it was blamed on <i>yaf</i>, poisons, and several interventions were tried to put an end to it, including help from traditional healers. When this didn't give results as expected, people moved on to a second explanation, <i>gemo</i>, which is a bad spirit that causes an epidemic. 49/50 of the adults interviewed in the study had believed Ebola was <i>gemo</i>. When it is believed that <i>gemo</i> is causing illness and death, prevention and control measures are put into place, including isolation. After EVD was confirmed by laboratory findings, the biomedical explanatory model was accepted as the explanation. However, most people did not necessarily think the disease could only be explained by one model.</p> <p><u>Issues of Concern</u> <u>Funerals and Burials:</u> it is the women's responsibility to clean the body of the dead and dress them before the funeral. Several high risk behaviors are related to the funeral, including touching of the body by the participants and transportation of the body. However, if death is believed to be caused by <i>gemo</i>, the rituals are adapted to limit contact with healthy individuals. If a person died in a healthcare facility, the family wasn't always around when the person died. When this was addressed as an issue, it was made up for by allowing the family to be part of the preparations for the burial. <u>Traditional healers:</u> was believed to increase transmission of EVD, especially after one traditional healer caused the death of more than 10 people. However, the conception of how this happened is not agreed upon. Some believe she continued to treat people while other think it was caused by people caring for her. Traditional healers were stigmatized. <u>Stigmatization:</u> 49 % of adults answered that they would not feel comfortable touching an EVD survivor one month after release from the hospital. However, many EVD survivors experienced stigma also after one month. Stigma included being banned from their homes, abandoned by their spouse or not being touched by their children. Sometimes this also happened to families of the EVD victim. The study found that woman experienced more stigma than men.</p>	<p>Checklist:</p> <p>Is the purpose of the study clearly formulated? Yes</p> <p>Is the method appropriate to give answers to the purpose? Yes</p> <p>Is the layout of the study appropriate to give answers the purpose? Yes</p> <p>Is the selection strategy appropriate to give answers to the purpose? Yes</p> <p>Were the data collected in a way that the purpose was answered? Yes</p> <p>Was background information that may have impacted the evaluation of data explained? Yes</p> <p>Are ethical conditions considered? No</p> <p>Is it clear how the analysis has been conducted? No</p> <p>Are the findings clearly presented? Yes</p> <p>Weaknesses</p> <ul style="list-style-type: none"> - Data was collected during a short period of time(16 days) - Researchers were not allowed to live within the communities, and could therefore not observe the culture first hand - Data was collected at the end of the outbreak <p>Strengths None mentioned</p>				
Conclusion	<p>Similar studies often only highlight the negative effects of cultural practices. There are both health-enhancing and health-lowering practices, as well as neutral. The local people know their situation best and need to be included in decision making and assessments of best practices.</p>						
Country	Uganda						
Year of data collection	Not stated						

Attachment 8

Reference: Abramowitz SA, McLean KE, McKune SL, Bardosh KL, Fallah M, Monger J, et al. (2015) Community-Centered Responses to Ebola in Urban Liberia: The View from Below. PLoS Negl Trop Dis 9(4):e0003706. doi:10.1371/journal.pntd.0003706			Design: Phenomenological study						
			Quality of evidence	IV					
			Strength of recommendation	B					
Purpose	Materials/methodes	Results	Discussion/comments						
<p>According to community leaders in Liberia, what are the best practices for containing Ebola? What would be their response if Ebola emerged in their community?</p>	<p>Data used in this study was collected as part of an assessment done by the Government of Liberia and the WHO, examining the view of community leaders on Ebola response. Data was collected in September 2014 in Monrovia and Montserrado County in Liberia. One focus group was established in each of 15 communities of different economic, ethnic and population background. Each focus group had 15-20 participants, with a total of 368 participants. All participants were community leaders of different sorts. The study is also based on information gathered through field notes and qualitative observations made through field work and community-based observations by the research team themselves. The data was analyzed by public health and anthropological researchers at University of Florida and Yale University.</p>	<p>The response from community leaders was analyzed and three phases of response were identified:</p> <p>1) <u>Prevention</u>: this was seen as the most important step to contain EVD. Participants agreed that this should include the following steps: community-based trainings, improved hygiene and sanitation, as well as personal protective equipment, surveillance of the disease, safe transportation of infected people, removal of the body of deceased EVD victims and creating a system for care of the ill in their communities.</p> <p>2) <u>Response and Treatment</u>: it was agreed upon that response teams was the best way to tackle this. However, it was reported that it might take time before response teams reached the community, or they might not show up at all. Therefore, it was suggested that trainings should be given in the communities, so that they knew how to take care of the sick themselves and how to prevent transmission to the rest of the community. The absence of or fear of taking infected people to hospitals or Ebola treatment centers(ETCs), led people to take care of their loved ones at home. Community leaders agreed that the sick and dead should be taken care of by hospitals or specialized staff, not by the communities.</p> <p>3) <u>Sequelae</u>: three main focus areas were addressed as part of the work in the aftermaths of the Ebola outbreak. i) reintegration of Ebola survivors into local communities, ii) care and management of "Ebola orphans", and iii) memorialization of individuals who have died of Ebola.</p>	<p>Checklist:</p> <p>Is the purpose of the study clearly formulated? Yes</p> <p>Is the method appropriate to give answers to the purpose? Yes</p> <p>Is the layout of the study appropriate to give answers the purpose? Yes</p> <p>Is the selection strategy appropriate to give answers to the purpose? Yes</p> <p>Were the data collected in a way that the purpose was answered? Yes</p> <p>Was background information that may have impacted the evaluation of data explained? Yes</p> <p>Are ethical conditions considered? Yes</p> <p>Is it clear how the analysis has been conducted? No</p> <p>Are the findings clearly presented? Yes</p> <p>Weaknesses</p> <ul style="list-style-type: none"> - Large focus groups(15-20 participants) - Questions in focus groups were hypothetical and focused on best practices, and therefore did not reveal the actual response, but rather how an ideal response <p>Strengths</p> <p>None mentioned</p>						
Conclusion			<p>The local communities need to be involved in the response against Ebola. They need to receive training to be able to tackle the disease until they get help, and they need to be heard when a response is prepared.</p>						
Country									
Liberia									
Year of data collection									
2014									

Attachment 9

Reference: Shultz, J.M., Cooper, J.L., Baingana, F. et al. The Role of Fear-Related Behaviors in the 2013-2016 West Africa Ebola Virus Disease Outbreak. <i>Curr Psychiatry Rep.</i> 2016 Nov. 18: 104. https://doi.org/10.1007/s11920-016-0741-y			Design: Case study
			Quality of evidence III
			Strength of recommendation D
Purpose	Material/methods	Results	Discussion/comments
Identify fear-related behaviors (FRBs) and see these in context with transmission of Ebola Virus Disease (EVD) during the 2013-2016 Ebola outbreak in West Africa.	Fear-related behaviors have been examined in this review by a multidisciplinary team, whereby links have been made between behavior and risk of transmission of Ebola Virus Disease (EVD). The methodology of this study is not properly explained in the article.	Several fear-related behaviors were identified in relation to transmission of EVD during the 2013-2016 outbreak: 1) <u>Providing care at home</u> : several factors influenced people to rather care for the ill at home, rather than taking them to a health care facility. The most common reasons of fear that resulted in home-based care were the fact that people who went to the treatment centers didn't return and the belief that healthcare professionals were harming or killing patients. This led to increased risk of transmission on several levels. 2) <u>Unsafe funerals and burials</u> : rituals of washing and preparing the body of Ebola victims poses a huge threat to non-infected individuals, but were not warned against by community leaders, because of the fear related to absence of traditional rituals. 3) <u>Fleeing from high incidence communities</u> : three reasons of migration were identified: i) fear of infection, ii) fear of stigma towards the community as a whole because of EVD, iii) fear of conflict. Migration in the time of the EVD epidemic increased deaths and transmission. 4) <u>Avoiding Ebola treatment</u> : sick people often avoided health care institutes, and some admitted patients even fled from treatment centers because of fear. This increased risk of transmission in their communities. 5) <u>Lack of health care workers</u> : because of the high risk of being in contact with both Ebola and non-Ebola patients, some health care professionals took sick leaves or left work completely in fear of getting infected themselves. 6) <u>Avoiding health facilities</u> : people feared health facilities in general because of the risk of being infected and because of the chance that they might be diagnosed with Ebola. It is estimated that because of these fears, 10 600 people died because of preventable diseases during the Ebola outbreak. 7) <u>Stigmatizing Ebola survivors and EVD families</u> : the more than 17 000 people who survived Ebola experienced stigma, rejection and abandonment both by family and society. 8) <u>Blaming, attacking and stigmatizing health workers</u> : in addition to the risk of getting infected at work, health workers also experienced targeting by people because of rumours that they were spreading the disease and killing people.	Checklist: Is the purpose of the study clearly formulated? Yes Is the method appropriate to give answers to the purpose? N/A Is the layout of the study appropriate to give answers the purpose? N/A Is the selection strategy appropriate to give answers to the purpose? N/A Were the data collected in a way that the purpose was answered? N/A Was background information that may have impacted the evaluation of data explained? No Are ethical conditions considered? No Is it clear how the analysis has been conducted? No Are the findings clearly presented? Yes Weaknesses None mentioned Strengths None mentioned
Conclusion			
Fear-related behaviors(FRBs) need to identified and addressed in an epidemic setting. Through interventions it is possible to modify FRBs to be of less harm to the society. FRBs can increase the risk of transmission, and therefore need to be prevented, mitigated and modified, to reduce the risk of harm in society.			
Country			
Sierra Leone, Guinea, Liberia			
Year of data collection			
Not stated			