

# The Experience of Control Measures for Individuals Affected by the Ebola Virus Disease in the North-eastern Region of the Democratic Republic of the Congo, 2019

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**Abstract:** To date, the Democratic Republic of the Congo is enduring its largest and longest Ebola virus disease (EVD) outbreak. This study aimed at exploring the experiences of control measures of Ebola outbreak. This was a qualitative study conducted in three health zones in three districts, namely- Katwa in Butembo city, Beni in Beni city and Mandima in Ituri Province. Thirty-eight participants were purposively selected. In-depth interviews were conducted. Thematic analysis was used to report qualitative findings. The results of this study showed that participants' experience of the EVD was marked by fear, fatality and mistrust of the response team rooted in the pre-existing distrust of the national authorities. The majority of participants strongly denied the existence of the Ebola virus considering it either as a political ploy to exterminate one ethnic group or as a scheme exaggerated for materialistic reasons. As a result, they showed hostile perception of control measures particularly the vaccination of contacts. However, during previous Ebola outbreaks in the DRC a positive perception of those measures was shown. We then concluded that Addressing the Ebola outbreak requires an adapted bottom-up communication that could help alleviate this lack of trust.

**Keywords:** Ebola, Outbreak, Experience, Control Measures

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## 1. Introduction

The Ebola virus disease [EVD] is a deadly zoonosis transmitted to humans from wild animals - mostly monkeys and bats - and spread to population through human-to-human transmission by close contact with the blood, bodily fluids, secretions or organs of an infected person, or objects contaminated by such fluids. Its average case fatality rate ranges from 25% to 90% [1, 2].

During August 2018, the Democratic Republic of the Congo [DRC] declared its tenth Ebola outbreak since 1976. This latest outbreak is by far the largest and longest ever to strike the country, with a death toll exceeding 2000 casualties with an overall case fatality ratio of 67% [2]. Lately an improvement has been noticed in terms of a decline in the

overall number of new confirmed cases and death. However, the disease continues to spread to new health zones [2].

This ongoing outbreak, unlike previous ones, is taking place in the north-eastern DRC, where waves of conflict have killed up to six million people since 1997 [3]. This complex political and security instability has led to the collapse of trust and social capital. As a result, violent attacks against Ebola centres and health providers are often reported in this region [2, 4]. Consequently, this has significantly hampered and delayed the response to the outbreak.

Nevertheless, national and local authorities and partners have been steadily working to gain control of the outbreak. The control of the epidemic includes quick identification and isolation of cases, control measures in hospital settings, identification and follow-up of contacts, and, very

importantly, safe burials [5]. These control measures are keys to preventing onward transmission of the virus [4, 6, 7]. A combined approach of these measures could stop the outbreak with an efficacy of 60% [8]. Some candidate vaccines have shown promising results in the cure and the prevention of EVD [9].

Compliance with control measures relies on trust and the perception of the population [4]. Previous experiences of subjects who have either directly been affected by EVD or who have been exposed to control measures may contribute to either reinforcing or alleviating the mistrust in the community. However, little is known of people's subjective experience of these control measures.

We therefore conducted a qualitative study that aimed at exploring experiences of previous EVD cases and beneficiaries of Ebola control measures during the ongoing outbreak.

The results of this study can provide to public health officials with useful insights on how control measures have been implemented and accepted, also on tailoring the ongoing responses to the outbreaks.

## 2. Method

### 2.1. Study Design and Setting

We conducted a qualitative study with the purpose of gaining more understanding on how people living in areas affected by the Ebola outbreak are experiencing control measures and how such measures have affected the community perception. We purposively chose three health zones in three of the most affected districts, namely- Katwa in Butembo city, Beni in Beni city and Mandima in Ituri Province.

### 2.2. Study Population

We purposively selected participants who had been directly or indirectly exposed to EVD using purposive sampling. The inclusion criteria were (10): 1) People who have been cured from EVD (15); 2) Family members of discharged patients (10); 3) Community members not affected but exposed to the Ebola control measures (11); 4) Front-line health providers, health centre head nurse (2). All the participants gave informed written consent prior to their participation.

### 2.3. Data Collection

We conducted an in-depth interview (IDI) with each of the selected participants. We used, for that, an interview guideline that included a series of open-ended questions covering four general topic areas in respect of the EVD as

follows: 1) participants' experience with EDV; 2) the support received by the participants when facing EVD; and 3) and participants' perception regarding control measures. For the purpose of this study, control measures were limited to quarantine, screening with rapid test, and vaccination. All the IDIs were conducted by skilled data collectors with at least five years of experience in data collection, a tertiary education and fluency in both French and Swahili. Swahili is the local language spoken in these communities. All data collectors received two days training prior to commencement of fieldwork. All the IDIs took place at a quiet and isolated venue to avoid any interference. They were all tape-recorded and transcribed verbatim in a Microsoft Word document file at a later stage. All the IDIs conducted in local language were translated into French.

### 2.4. Data Management and Analysis

Transcripts were read and reread to identify themes and patterns of response across categories and individuals. They were coded and categorized by two researchers, using Microsoft Excel software matrix. Codes were deductively assigned referring to the interview guide; emergent codes were inductively identified from collected data. Quotes were drawn out to ensure that participants' stories were upheld and to explore the interrelation among different themes. Triangulation was used to enhance the credibility of data analysis.

In addition, the socio-demographic data were collected and analysed using Microsoft Excel software and SPSS software 20th version. Results of socio-demographic data were presented in tables of frequency and percentage or mean and standard deviation for normal distribution or median.

### 2.5. Ethical Issues

An ethics review of this study was approved by the Ethics Board of Kinshasa School of Public Health before beginning this study. Informed written consent was obtained from all participants. To ensure the confidentiality of participants, their names and other identifying information were not collected.

## 3. Results

Overall, this study included 38 participants- 15 survivors, 10 family members of patients discharged, 11 community members and 2 front-line health providers. Both female and male were similarly represented. The majority of participants had reached at least secondary (high school) level and had a remunerative occupation.

Table 1. Study population characteristics.

Variables	Modalities	Survivors	Family members	Other community members	Health providers	Total	%
		n=15	n=10	n=11	n=2	n=38	
Age	Mean (STD)	27,5 (14,4)	40,3 (19,3)	39,1 (11,1)	40,0 (4,2)	35,2 (14,4)	
Sex	Female	9	4	6	1	20	52,6
	Male	6	6	5	1	18	47,4
Education	None	3	3	2		8	21,1

Variables	Modalities	Survivors n=15	Family members n=10	Other community members n=11	Health providers n=2	Total n=38	%
Occupation	Primary	4	1	2		7	18,4
	Secondary	4	6	3		13	34,2
	Higher	4		3	2	10	26,3
	Ambulance driver	2				2	5,3
	Carpenter	1				9	23,7
	None	3	3	3		1	2,6
	Trader			1		1	2,6
	Farmer	2	5	2		9	23,7
	Student	5		1		6	15,8
	Nurse	2		2	2	6	15,8
	Taxi driver		1	1		1	2,6
	Veterinary		1			2	5,3

### 3.1. Participants' Experience with EDV

With this first topic, participants were to tell the story about their own experience of Ebola. Three subthemes emerged: contact with Ebola, feelings and denial.

#### 3.1.1. Contact with Ebola

All the participants spontaneously evoked their encounter with Ebola. A majority of the participants had contact with another Ebola case mostly a relative (parents, partners, children...). Others mentioned coming into contact with the virus during a funeral in the neighbourhood or at the hospital.

"My mother first died of an incurable disease, after 21 days my father died, I kept my parents myself... and my husband had just been confirmed sick," said a 32-year-old female survivor.

"I was contaminated when we went to bury a neighbour who died of Ebola. Due to ignorance, we refused to observe the Ebola response team measure on not to bury his body because we did not believe in this disease," said a 40-year-old male survivor.

"I got infected at the paediatric clinic. I handled a toddler with respiratory distress in November 2018 unaware of the existence of Ebola," said a 39-year-old female nurse survivor.

#### 3.1.2. Feelings

Participants evoked how they felt when they were faced with Ebola. For most of them, stress, fear, fatality, satisfaction with being cured and hostility to the response team were the feelings that mostly emerged.

"I have a very bad memory of this disease. In accordance with all we had learned about Ebola, I had no hope of healing. I felt like a person who is already dead," said a 29-year-old female survivor.

"I can say that I am completely disappointed to have lost my parents: my mother and my dad and my little brother. Ebola is a demon, a bad spell. What is hurt is that, people take advantage of it to get richer and to lie on us," said a 20-year-old family member of a discharged patient.

"I felt like someone who is already dead but I thank the doctors who treated and saved me," said a 26-year-old female survivor.

#### 3.1.3. Denial

Some participants either rejected EVD considering it as an

invention to rob the population or a sort of a poison created to "exterminate" the young and active population. As a consequence, they rejected or were hostile to all the control measures that come with it. This denial was even shared by some survivors.

"I would say beforehand that Ebola does not exist, it's really an outright montage. I lost my daughter... my daughter was uncomfortable and decided herself to go to the centre for the Ebola care centre (ECC) even though I did not agree. She was told that she had Ebola and died the next day... she did not look so seriously ill...they had kept me at ECC for three days and according to them the result was negative. They are liars, they said my result was negative because I'm old, but if I was still young, they would have killed me and after declared it was Ebola," said a 70-year-old female community member.

"I still have some doubt to say anything about this disease even though I was a victim," said a 31-year-old male survivor.

#### 3.1.4. Support When Facing EVD

With this topic, participants were asked to talk about the support they received before, during and after facing the EVD. Before coming into contact with the EVD, only very few were aware of the EVD and those who knew about it received information from other members of the community, who were in the majority hostile to the Ebola riposte team. When they suspected that they were developing Ebola, the participants contacted the response team but some of them first had to be brought to ECC before they received support from the members of the response team, the most cited were psychologists and doctors. At the ECC, most of the participants mentioned the positive role played by the response team; they did, however, complain of being unable to interact with their relatives since they were forbidden even to use a telephone. For those who survived, they mentioned regular visits from a psychologist.

"No, we did not have enough explanations from the nurses who treated our dad. Something we did not like because we should be well-prepared from home to better accept care. So your doctors or nurses still need training," said a 30-year-old male family member.

"I learned that this disease came from Beni. Nobody had ever explained to me how it was transmitted. Until my parents got infected and died. I am really discouraged," said a

25-year-old male family member.

"I was well prepared before going to the hospital even though I did not want to go because for me, going to the hospital was synonymous with being delivered in the hands of the riposte team... But finally, we had to adapt to the multiple advice received from doctors who treated me," said a 19-year-old female survivor.

"In ECC, they deprive patients of a telephone. They can no longer communicate with family members," said a 30-year-old female family member.

"Apart from my family members and friends, there is a boy who visited me regularly, and he said that he is a psychologist and a riposte. He just wanted to make sure of my recovery," said a 25-year-old female survivor.

### 3.2. Participants' Perception on Control Measures

To get a better understanding on how their experience altered their perception toward control measures, participants were asked to give their opinion regarding the existence of Ebola, the importance of quarantine, screening and vaccination.

#### 3.2.1. Existence of Ebola

Participants disagreed among themselves as a group. Particularly those who suffered from EVD, family members of discharged patients and healthcare providers, were convinced that Ebola is real and is transmitted by bodily fluids. On the other hand, some participants were sceptical about the existence of Ebola considering it either as a political tool used by the national authorities to exterminate members of one ethnic group or a way to make money on the back of the population. Even among those who agreed on the existence of Ebola, some still pointed out the role of greed in the management of the outbreak. The riposte team is often accused of creating fake new cases in order to be paid.

"I cannot say that Ebola does not exist because I was myself a victim," said a 19-year-old female survivor.

"I believed at this disease just at the beginning. But today I have the impression that this disease does not exist, because it has become like trade. People are happy when there is a positive case because they will get well paid. Ebola is an invention and everything that goes on in Ebola is masquerade," said a male community member.

"In my opinion, The Ebola in Butembo / Beni is different from others; it is just another way of eliminating our population because despite the war in the East, the Nande people are getting developed and organized themselves better compared with other parts of the country. Thus, it was necessary to manufacture another more powerful weapon to silently kill and impoverish us," said a 45-year-old female community member.

#### 3.2.2. The Importance of Quarantine and Screening

Participants were asked to give their opinions on the usefulness of quarantine. As for the first subtheme, participants expressed divergent opinions on the importance of quarantine. While, most of the patients who were

discharged and their family members had a positive view of the quarantine, some pointed out its harmfulness since many who were put in quarantine developed EVD and died.

"Quarantine can slow down the disease because it allows the suspect not to contaminate his family members. In the isolation at the ECC, the hygiene measures are respected and each patient is in his cell," said a 69-year-old male family member.

"I hated my mother's quarantine. It was a bad practice. People always get sick and we do not take them to the ECC. They kept my mother for 3 days and then they killed her. My father already died two weeks before, it was me who touched him and washed his clothes when he was sick. I did not get vaccinated but I'm still alive 3 months later," said a 25-year-old male family member.

#### 3.2.3. The Importance of the Vaccination Against EVD

This subtheme was even more controversial as the majority voiced their scepticism a vaccination. Moreover, for the majority, the vaccine was useless since even those who were vaccinated still developed EVD and died. For some, it was a mass chemical weapon for the extermination of the Nande people.

"Ebola is a reality. However, the population is still ignorant especially since this disease occurred in a context of insecurity and people think that it is another way to eliminate the population. We, who were victims, ended up understanding. I encourage people to get vaccinated and tested but they do not believe me and say that I was corrupted by the riposte team," said a 32-year-old female family member.

"I do not agree. The Ebola here is not a reality, even though it may have been a real disease in other places. Here at home, it's politics and moreover their vaccine is not good. They gave it to my grandchildren and all died. So, despite being vaccinated, I do not trust this vaccine and I cannot encourage anyone," said a 30-year-old male family member.

## 4. Discussion

This study aimed at exploring the experience of people who have faced in one way or another the EVD, in order to get a better understanding of how control measures influenced the view of the population living in affected areas and the community commitment to fighting this outbreak. We discovered that when participants recalled their experience with the EVD, fear, stress, fatality and mistrust were the most dominant feelings due to their contact with the virus. The place of fear during outbreaks is well- documented [10–12]. It is a normal 'adjustment reaction' when facing a crisis such as an Ebola outbreak [13]. It can trigger the "fight or flight" response that can rapidly expand among members of the community [14]. This, if not addressed, can cause some people either to leave or adopt some reactions such as mistrusting the riposte team here often suspected of complicity with the political authorities, who want to exterminate the population or to fuel the outbreak for

materialistic reasons. The high fatality rate of Ebola and the non-existence of a cure further exacerbate this fear. Addressing the emotional side of the crisis is therefore as critical as providing medical explanations for the problem and can improve the compliance of the community to control measures.

Most of the survivors often reported having been contaminated when caring for an infected relative but also to some extent, through contact with EVD cases at the hospital and/or burial of a neighbour. This can be translated, like during the West African epidemics [15], either as a consequence of ignorance or mistrust as many were unaware of the disease at the beginning of the outbreak or were influenced by the community mistrust and hostility to the riposte team. The ignorance could also reflect a poor sensitization of the community already distrustful of the national authorities. This mistrust of the riposte team is probably and mainly rooted in a chaotic political and insecurity situation that this region has experienced for decades [4, 16].

As for the control measures, the scepticism reported by this study not only reflects a bad experience which some participants had in respect of the EVD but also a failure to appropriately communicate with the affected population. In fact, some considered the quarantine as useless and even dangerous as most of those quarantined ended up infected and died. It appears that the population was not provided with enough information about quarantine and what to expect from such measure [7, 11, 17].

The hostility to the vaccine was even more pronounced as many considered it either useless since the vaccinated people still died from the EVD or as a weapon for a mass extermination of one ethnic group. While this can also be explained by a failure to better engage in a thorough communication with the population, the impact of the internet [18] and the open conflict between the previous Ministry of Health and the new coordination team on the introduction of the new candidate vaccine have negatively influenced the perception of the community on Ebola. In fact, social networks are loaded with messages hostile to the vaccination and the resignation letter of the previous Ministry of Health is often used for that purpose.

One point of satisfaction is that those who have been healed from the EVD have over time improved their view of the EVD as they showed a positive opinion on the control measures despite local scepticism. This positive attitude can be an opportunity that could be exploited to overturn the local misperception of the EVD.

As for the limitations of this study, this study is a qualitative study in which saturation may have not been reached because of smallest number of participants. Therefore, we cannot reject that other subthemes could have emerged with a bigger sample. We cannot completely exclude information bias that may have occurred during the interview as on one side, the interviewer may have distorted (inadvertently or expressly) the questions and, on the other side, the interviewee, given the overall sceptical environment,

may have given “socially ideal” responses. It is noteworthy that efforts were made to mitigate those limitations by carefully selecting data collectors based on their skill in conducting qualitative studies and their knowledge of the context.

## 5. Conclusion

This study explored the experience of people living in areas affected by Ebola who directly or indirectly dealt with Ebola. Fear and distrust of the national authorities as well as mistrust of the response team have driven people’s perception and compliance of control measures. The first information received about Ebola by the population, mostly through social networks, contained erroneous information. This fuelled the distrust that the population already had toward the local et national political authorities and rendered them more sceptical toward the response team. Not taking into account pre-existing rumours in the beginning of the outbreak reduced the chance to see the population respect those control measures. It is therefore necessary to set up a communication strategy involving community leaders and other active community forces to address rumours and misinformation in order to convince the population to adhere to the control measures.

On the other side, it is clear that the discharged patients or the population who experienced the control measures have a good opinion of them. They may therefore be the proof of the effectiveness of such measures and could help overturn this skepticism noticed among some community members.

Thorough explanations on the vaccines used during this outbreak is also needed in order to remove some confusions exacerbated by the open conflict between the former minister of health and the coordination team.

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## Authors’ Contributions

PBM wrote the proposal, supervised the data collection, analysed collected data, wrote this manuscript; other authors participated in the reviewed of the manuscript.

## Disclosures About Potential Conflict of Interest

The authors declare that they have no competing interests.

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