

# Community Compliance to the Ebola Outbreak Control Measures in the North-eastern Region of the Democratic Republic of the Congo in 2019

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**Abstract:** The Democratic Republic of the Congo is enduring; since 2018, its tenth and deadliest Ebola outbreak already over 2000 deaths have been claimed. Compliance to control measures relied on trust and the perception of the population. This study aimed at exploring the perception of people living in areas affected by the Ebola virus disease (EVD). This study was a descriptive qualitative study conducted in three health zones in three of the most affected districts: Katwa in Butembo city, Beni in Beni city and Mandima in Ituri Province. One hundred and three participants were purposively selected. In-depth interviews were conducted using a guide that included open-ended questions on: 1) Participants' experience of the EDV; 2) Perception of the Ebola outbreak; 3) Perception of self-vulnerability; and 4) Perception of the effectiveness of control measures to stop the outbreak. Thematic analysis was used to report qualitative findings. The results of this study showed that participants' experience of the EVD was through members (relatives, friends, neighbours...) of the community who were either infected or in contact with the virus. Their perception of the symptoms, the management and the outcomes of these episodes were keystone of the way in which they comprehended the disease. Some members of the community questioned the diagnosis since several cases did not develop haemorrhagic symptoms. Participants showed some confidence on their own vulnerability to the disease and were convinced, to some extent, that this outbreak could be stopped if those control measures were respected. However, the denial of the outbreak fueled by political distrust still remains challenging. We concluded that addressing the Ebola outbreak requires an adapted bottom-up communication that could help alleviate this lack of trust, improve community perception and therefore, of the disease.

**Keywords:** Ebola, Outbreak, Perception, Compliance

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## **1. Introduction**

The Democratic Republic of the Congo (DRC) is enduring; since 2018, its tenth and deadliest Ebola outbreak already over 2000 deaths have been claimed [1]. While the trend of new cases of Ebola virus disease (EVD) has significantly decreased, a serious concern is the amount of new cases that are not linked to any previously known chains of transmission. This continued seeding of the virus into new areas represents a constant risk of the extension of

the epidemics [2]. In fact, new cases have been recently reported from South-Kivu, a province not previously affected by the EVD and no clear history of a stay in an affected area [1].

Ebola creates a disruption of the social fabric since social and moral behaviours such as exchanging of greetings, caring for the sick and burials are restricted [3, 4]. Outbreaks of serious illnesses like the EVD also provoke a feeling of the "fear of death" among affected communities that can lead to adverse reactions such denial, mistrust among community

members or toward the health system [5]. This should therefore be taken into account when responding to such outbreaks.

The current outbreak is occurring in the north-eastern (North-Kivu, South-Kivu and Ituri) region of the DRC, a political and security unstable region that has been through a wave of armed conflicts killing over six million people since 1997 [6]. This has created a lack of trust in the local and national political authorities and, in the effectiveness of the response team. The coercion for activities such as burials, tracking of contacts and isolation has even further exacerbated that lack of trust and pushed the affected community to opt out by some negative behaviours such as attacking treatment centres and health workers, hiding cases and contacts in the communities or even refusing to let the response team safely bury the deceased [7, 8].

Management of epidemics relies on compliance to control measures such as quick identification and isolation of cases, control measures in hospital settings, identification and follow-up of contacts, and, very importantly, safe burials [9]. Encouraging members of the community to comply with such measures has proved useful in containing previous outbreaks. In fact, a combined approach of these measures could stop the outbreak with an efficacy of 60% [10]. However, motivating the community to comply can be difficult particularly in such a context of suspicion. People may be more likely to comply with health related control measures if they believe: that the recommended measures are effective; they perceive a self-vulnerability to be affected by the outbreak; they perceive that the illness has severe consequences; they believe that the illness is difficult to treat; and they trust the government's ability to manage the outbreak [11-13].

A deeper understanding of local perceptions is therefore essential in order to learn lessons and potentially adapt ways to increase appropriateness, acceptability and so effectiveness of control measures by the affected communities [14]. However, studies addressing this issue in that specific war-torn area are scant. This study therefore aimed at exploring the perception of people living in affected areas. We undertook this study to provide public health officials with useful insights to help them recalibrate the response to the Ebola outbreak.

## 2. Method

### 2.1. Study Design and Setting

A qualitative study was carried out in three health zones of three of the most affected districts: Katwa in Butembo city, Beni in Beni city and Mandima in Ituri Province.

### 2.2. Study Population

We purposively selected participants to include: 1) Men aged 18-29 years old (20); 2) Men aged at least 30 years old (32); 3) Women aged 18-29 years old (19); 4) Women aged at least 30 years old (18); and 5) Community leaders (chiefs of

villages, teachers and religious leaders) [14]. A total of 103 participants were interviewed.

### 2.3. Data Collection

We conducted a one-on-one in-depth interview [IDI] with each of the participants. We used, for that, an interview guideline that included a series of open-ended questions covering four general topic areas:

1. Experience of Ebola;
2. Perception of the EVD outbreak;
3. Perception of self-vulnerability; and
4. Perception of the effectiveness of control measures to stop the outbreak.

All the IDIs were conducted by nine skilled data collectors with a tertiary education and fluency in both French and Swahili. They all received two days training before commencing fieldwork. Training was performed by three public health specialists. All the IDIs took place in a quiet and isolated place to avoid any interruption. They were all tape recorded, before being transcribed verbatim in a Microsoft Word file at a later stage. All the IDIs that took place 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 the 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

This study proposal was approved by the Ethics Board of Kinshasa School of Public Health. Informed consent was obtained from all participants. To ensure the confidentiality of participants, their names and other identifying information were not collected.

## 3. Results

This study included 103 participants with an average age of 36 years old. Two thirds of the participants were males and reached at least the secondary high school level of education. The majority of the participants had a remunerative job. Farmers represented one fifth of the total participants (Table 1).

**Table 1.** Study population characteristics.

Variables	Modalities	n=103	%
Age	Mean (STD)	36.2 (11, 9)	
Sex	Femme	39	37,9
	Homme	64	62,1
Education	None	15	14,6
	Primary	18	17,5
	Secondary	61	59,2
	Tertiary	9	8,7
	None	20	19,4
Occupation	Chief of village	3	2,9
	Tailor/Seamstress	3	2,9
	Farmer	22	21,4
	Teacher	6	5,8
	Student	9	8,7
	Nurse	3	2,9
	Carpenter	3	2,9
	Religious leader	6	5,9
	Taxi driver	2	1,9
	Vendor	13	12,6
	Others	13	12,6

Four topics were discussed with the participants: experience of the EVD; perception of the EVD outbreak; perception of self-vulnerability to the EVD; and perception of the effectiveness of control measures to stop the outbreak.

### 3.1. Experience of the EVD

Four subthemes emerged from this topic: existence of Ebola, knowledge of an Ebola case, Ebola symptoms, Ebola case management and outcomes.

#### 3.1.1. Existence of Ebola

While the majority of participants recognized the EVD as a real disease, some still questioned its existence. Some participants considered the EVD as a poison used to exterminate the Nande ethnic group for political reasons. Other participants declared that the EVD was just a pure exaggeration, of existing diseases such as malaria that share the same symptoms, for materialistic reasons.

“From one pastor experience, everyone in my community now knows that Ebola exists. It was at the beginning that some people were pessimistic with the increase in death rate. They have finally come to understand,” said a 45-year-old man.

“In my opinion, the disease does not exist because the signs of Ebola they told us do not occur in so-called Ebola patients; for example, we had been told about haemorrhage, but people who die of Ebola do not have haemorrhagic signs. In the community, most are not convinced for the same reasons; they say, it's politics,” said a 29-year-old woman.

“Ebola is a complete fabrication because those who are vaccinated get some incentive like rice and other items. Also, people working there earn a lot of money while local nurses can easily do the same job,” said a 30-year-old woman.

#### 3.1.2. Knowledge of an Ebola Case

A majority of participants knew someone [relatives,

friends or neighbours] who were infected. Some were directly affected either as discharged patients or previous contacts. Few participants, mostly among those ignoring the existence of the disease, reported not knowing anyone affected by the disease.

“I know several people who have been sick and others who have died of Ebola. The dead are more numerous than the healed ones,” said a 42-year-old man.

“I do not have Ebola experience because this disease is fake,” said 22-year-old man.

#### 3.1.3. Ebola Symptoms

For most participants, fever, vomiting and diarrhoea were the most cited symptoms. Unexpectedly, only less than half of the participants cited haemorrhaging “blood everywhere” among the symptoms. Some even challenged the existence of Ebola since most of the cases they knew of had not developed any haemorrhaging.

“Nurses said that the Ebola disease is like malaria, the only difference is that in malaria you do not lose blood but in Ebola you have to lose blood either by the nose, the mouth, the ears,...” said a 25-year-old woman.

“The signs of Ebola are similar to those of malaria: vomiting, headache, fever...” said a 50-year-old religious leader.

#### 3.1.4. Ebola Case Management and Outcomes

Many participants reported the collection of cases and contacts by response team as soon as a case or a contact was reported to them. All cases were in isolation and contact with their relatives was restricted. Contacts were also reportedly kept in the Ebola treatment centre [ETC] where they were vaccinated and kept in isolation while awaiting their Ebola test results. As for the outcome, a majority reported that many who went to the ETC died. This contributed to the negative image that some have of these centres. Some cases of resistance to the response team were also reported.

“The pastor's mother had agreed to go to the ETC, she had the vaccine beforehand and she is alive today. His sister, on the other hand, who had fiercely opposed the riposte, is no longer alive. We have already been vaccinated,” said a 45-year-old man.

“I know people who have been affected by the diseases... They consulted the nurse at the health centre... and they were sent to the ETC. A few days later, we learned that they all died. Their relatives fled because they did not want to be followed by the response teams and did not want to receive the vaccine either. According to them, they had experimented if the fact of being exposed and not being vaccinated exposed to the disease. And since they did not develop the disease, they concluded that the disease does not exist and that it is rather the vaccine that is poisoned and that causes the disease,” said a 28-year-old male.

### 3.2. Perception of the EVD Outbreak

For a majority of participants, the EVD spread to their communities through contact with people who moved from

affected areas to their communities. Many also cited nurses' interaction with those contacts as the gateway through which the disease penetrated the community. For the most sceptical, Ebola was either a poison used to exterminate the Nande ethnic group or witchcraft.

"The disease came from where she had started in Mangina with people already infected who fled to Beni. So far, it has spread all over the city to North-Kivu province," said a 27-year-old woman.

"By a nurse... who was in contact with a case of Ebola in North-Kivu, she had fled the vaccine and by her, the disease arrived here," said a 40-year-old man.

"Supposedly by a nurse. It does not exist, it's politics and the bad spirit. It's the end of the World," said a 50-year-old woman.

### 3.3. Perception of Self-vulnerability to EVD

When asked if they could get contaminated, a majority of participants were split between those who believed that they could not get infected either because they were vaccinated and/or respected all the measures taken by the response team and those who relied on God's protection and considered themselves as protected. A minority considered themselves as vulnerable because they were living in affected areas. The most sceptical considered themselves as unconcerned about this "fake" disease.

"I can get Ebola because it's a very contagious disease and if I do not respect hygiene and have been in contact with someone who has Ebola," said a 25-year-old female.

"No, because God cannot afford it," said a 24-year-old man.

"I cannot catch this imaginary Ebola of Butembo but if it was the real Ebola like the one that occurred in Equateur, yes" said a 28-year-old male.

"Me no! Since I am already vaccinated, a vaccinated can no longer catch Ebola," said a 50-year-old man.

### 3.4. Perception of the Effectiveness of Control Measures to Stop the Outbreak

When asked whether control measures could help end the Ebola outbreak, two subtopics emerged: the first, relating to the management of the outbreak; and the second, to the particular case of vaccination.

#### 3.4.1. Effectiveness of the Management of the Outbreak

A majority of participants responded in the affirmative to the question that Ebola could be stopped. However, while some conditioned the end of the outbreak by the compliance to control measures, for others, it was more about fixing the political problem and removing this poison. The most sceptical of the participants evoked the fact that the outbreak was an opportunity for many to make money.

"Yes, the community must follow precautionary measures and the authorities must get involved," said a 20-year-old woman.

"It is very difficult to stop this disease because it gives money to some, so stop paying a lot of money to the

people of the response and punish people who do not work well," said a 59-year-old man.

"As it is a fake Ebola, when the authorities who invented this disease will want to stop it, they will do it," said a 45-year-old man.

#### 3.4.2. Perception of the Vaccine

Among all the control measures, the vaccine caused the most reaction. A majority of the participants considered the vaccine to be effective in preventing the EVD. However, others, almost one third, still considered this vaccine as harmful to the population.

"Yes, the vaccine exists but people are dying even after being vaccinated and we cannot vaccinate everyone according to the teams of the response and we do not understand why," said a 45-year-old village chief.

"For me the vaccine is good but it does not reduce the severity of the epidemic since even those who are vaccinated always falls ill," said a 36-year-old male.

"As I was close to an Ebola case who died, I got vaccinated and it is a good vaccine," said a 24-year-old woman.

## 4. Discussion

This study aimed at exploring the perception of people living in areas affected by Ebola in order to get a better understanding of why community commitment to fighting the disease is still low and what can be done to improve it. We found that participants' experience of the EVD was through community members (relatives, friends, neighbours...) who were either infected or in contact with the virus. Their perception of the symptoms, management and outcomes of these episodes were keystone of the way in which they comprehended the disease. Particularly, the perception of isolation and vaccination was drawn out from previous experiences. Participants considered isolation as a "place where people go and die" and the vaccine ineffective as it did not prevent people from being contaminated. It therefore appears, in line with previous literature, that these experiences shaped: their perception of the outbreak; the perception of their own vulnerability to the EVD and; the perception of the vulnerability of the outbreak to control measures [14, 15]. Moreover, rumours and resistance noticed among respondents were also a product of those experiences [3].

Also, the fact that many of those who were taken to containment died, further exacerbating the suspicion that some had of the EVD response team. Some blamed the quarantine for being useless and dangerous and others likened it to a place where people were poisoned and killed. This is similar to what was experienced in Liberia with regard to the quarantine measure [16]. In fact, it appears that the population did not get enough information on what quarantine entails and what to expect from such a measure [16-18]. Failure to correctly communicate with the population might have a negative impact, bring disbelief to all the responses and recommendations among the affected

population [19, 20] while trust can break down barriers that are preventing or constraining cooperative behavior [21].

As for the experience of the EVD, it has been revealed that the role of the response team in sensitizing the symptoms and what measures to take when facing Ebola was recognized as positive by a majority of participants. However, failure to correctly explain the symptoms of the disease brought about confusion among some members of the community who questioned this diagnosis since several cases had not developed haemorrhagic symptoms. Therefore, they were more sceptical and wondered if some cases of malaria were not wrongly or purposively diagnosed as Ebola. As happened in Sierra Leone [19], a requirement for a better explanation of the similarities between Ebola and other diseases. Furthermore, much is yet to be known on the physiopathology of the EVD. Bleeding during the EVD, formerly known as Ebola haemorrhagic fever, was found to be less frequent during the West African outbreak and occurred mostly at a later stage of the disease. This was explained as a consequence of the Ebola virus disease's adaptation to the human host [22]. Consequently, communication on the EVD has also to recognize and incorporate this uncertainty [23].

Participants recognized that the contact with cases or contacts fleeing affected areas was as a gateway to Ebola in their communities. This could be read, like during the West Africa epidemics [24], as a consequence of ignorance at the early stage of the outbreak since many were unaware of the disease and could not take necessary control measures [14]. The ignorance could also reflect a poor sensitization of the community already distrustful of the national authorities [8, 25].

The hostility against 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 clear communication with the population, the impact of the internet [26] and the open conflict between the previous Ministry of Health and the new coordination team on the introduction of the new candidate vaccine is not negligible. In fact, social networks are loaded with messages hostile to the vaccination and the resignation letter of the previous Minister of Health is often used for that purpose. Study on the acceptance of a vaccine during outbreaks suggest that the main promoting factors are the perceived risk of contracting the infection and the belief in its efficacy [12]. This perceived ineffectiveness could also account for the resistance by some community members to get vaccinated.

Despite all of the aforementioned, it also appears that by sensitizing community members: it helped to build their confidence; they felt less vulnerable to the disease; and believed that the outbreak could be stopped, if they complied with the control measures. This shows, to some extent, the effectiveness of sensitizing the population to adopt good behaviours. However, efforts are still needed to convince the most sceptical to become even more effective.

This study has some limitations among which we cannot

completely exclude the information bias that may have occurred during the interview as on one hand, the interviewer may have distorted (inadvertently or expressly) the questions and, on the other hand, the interviewee, given the overall sceptical environment, may have given "socially ideal" responses. Efforts were nevertheless 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 population perception of the EVD and showed how initial experience with Ebola shaped community perception of the disease. The failure to provide correct information has brought about some confusion in terms of what constitutes the Ebola virus disease and what does not. Such confusion and the distrust of political authorities have played a big role in how people comply with the control measures. Therefore, efforts should be made to engage in communication with the affected communities in order to build confidence and trust. As already recognized, good communication can have the effect of not only reducing fear, but also promoting self-protecting behaviours, and preventing misinformation. [23] The involvement of community members, for instance discharged patients who have had a positive experience of the outbreak could help overturn this scepticism. Addressing the underlying distrust of the political authorities by a thorough dialogue with leaders of different communities is also fundamental to building trust of community members.

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