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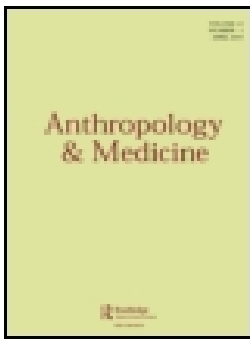
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# 'They'll inject you and you'll die': from medication non-compliance to acceptance in Guinea's Ebola treatment units

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## ABSTRACT

During the 2013–2016 West African Ebola epidemic, medical emergency response teams negotiated a context marked by public hysteria and fear to prevent the spread of the virus and treat those already infected. However, the presence and work of Ebola response teams added to suspicions provoked by the rapid increase in numbers of dead and dying and by locally unintelligible emergency measures. Based on data collected from 40 young adult 'survivors' between 16 and 29 years of age who were hospitalized for Ebola during the epidemic, this article examines how pharmaceutical treatments were accepted (or not) by patients in ebola treatment units (ETU). Three key questions guide this analysis: (1) Did hospitalized individuals adhere with or refuse treatments offered at ETUs? (2) Did their attitudes change over the course of their hospitalization? (3) Which factors influenced refusal of treatment or compliance? To the authors' knowledge, no previous studies have explored the resistance of hospitalized patients to treatment in Ebola centers. This article, in addition to exploring patients' practices and related perceptions of treatment with evolving meanings in this outbreak crisis situation, also presents practical recommendations for future Ebola interventions as well as theoretical knowledge about the circulation and transformation of socially constructed representations of medications.

## ARTICLE HISTORY

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## KEYWORDS

Ebola; Guinea; medication; treatment; resistance

## Introduction

The 2013–2016 West African Ebola virus was the largest of its type, resulting in almost 30,000 cases and 11,000 deaths mainly in Guinea, Sierra Leone and Liberia (WHO 2016). While resistance to Ebola response interventions was seen in varying degrees in all three countries, this resistance (also referred to as 'reticence') was more visible in Guinea than in the other countries affected by the outbreak (ACAPS 2015). Resistance was a broad term used to cover everything from hiding from response teams coming to identify suspected cases to the killing of eight Ebola response agents in the village of Womey in September 2014. UN agencies, governmental, and non-governmental organizations worked to address

this distrust, while at the same time putting in place emergency measures to stop the epidemic. Anthropologists were also brought in to specifically describe and address this resistance as well as propose ways of making interventions more acceptable to local populations (Abramowitz 2017).

The extreme distrust of the Ebola response in Guinea was linked to multiple historical and social factors of domination as well as attitudes of general distrust toward the Guinean State and its intentions (Gomez-Temesio and Le Marcis 2017). Because the Ebola epidemic first emerged in areas of the country largely inhabited by political and ethnic minorities, the politicization of the fight against Ebola led to a genocidal interpretation of the response by many who thought that the response was intentionally trying to exterminate certain populations (Wilkinson and Fairhead 2017). This suspicion was magnified by visions of a state already seen as greedy and not trustworthy (Fribault 2015).

One of the most important interventions of the Ebola response was the establishment of Ebola Treatment Units (ETUs), where individuals suspected to be infected were taken (sometimes against their own will) for testing, observation, isolation, and 'treatment'. Since no antiviral treatment was used routinely, this treatment consisted of medications to manage fever, nausea, diarrhea, malaria, dehydration, and malnutrition. While these medications supported the overall health of those infected with the virus, they did not necessarily guarantee recovery. Populations living in outbreak areas were targeted with messages that seemed to be contradictory: encouraging them to seek treatment for Ebola from an ETU if they suspected infection, and at the same time warning that there is no treatment that can work against Ebola.

These ETU have been described by anthropologists as potential 'hotspots', i.e. spaces of high epidemiological risk of transmission (Brown and Kelly 2014) managed under biosecurity imperatives and experienced by patients as coercive environments with psychotraumatic features. Gomez-Temesio and Le Marcis (2017) describe the doors of the ETU as symbolizing a passage toward the loss of ordinary social links and status with 'entrance into ... a world of violence legitimized by biosecurity protocols' (p. 16, our translation). The confrontation of fellow patients' deaths and the disruption of social and gender orders shaped the environment of ETU particularly during the peak of the outbreak. Although Western pharmaceutical treatment is often very popular in West Africa and other regions in the Global South for its efficacy and 'modernity' (Van der Geest and Reynolds Whyte 2003), the treatments offered at these sites were situated within a very unique context where attention should be paid to 'the divergent practices of care and protection that shape institutional spaces' (Brown and Kelly 2014, 289).

Both macro- and micro-processes shape resistance to and demand for medical services and treatments. In this paper, we hypothesize that, although processes on different scales may have similar impacts on behavior, examining changes in individual perceptions is valuable to understand how these are translated into action, and how these actions may feed into macro-level forces. During this outbreak, despite research focusing on distrust of the Ebola response in Guinea and radical acts of resistance and violence toward Ebola response workers by target communities, no previous studies have explored the resistance of hospitalized patients to treatment in Ebola centers.

This article specifically examines how pharmaceutical treatments were accepted (or not) by patients at ETU within the context created by the coexistence of messages from health institutions with contradictory meanings about treatment and a general feeling of social

distrust and resistance towards the Ebola response. This leads to three key questions which will be explored in detail through this paper: (1) Did hospitalized individuals adhere with or refuse treatments offered at ETUs? (2) Did their attitudes change over the course of their hospitalization? (3) Which factors influenced refusal of treatment or compliance? This study, in addition to exploring patients' practices and related perceptions of treatment with evolving meanings in this outbreak crisis situation, contributes to practical recommendations for future Ebola interventions as well as theoretical knowledge about the circulation and transformation of socially constructed representations of medications.

## Methods

Participants in this research were from the Postebogui Project cohort, which was set up first in Conakry (Guinea) and provides multidisciplinary research monitoring of 802 Ebola survivors who were recruited between March 2015 and July 2016.<sup>1</sup> Data analyzed in this article were collected from 40 young adults between 16 and 29 years of age. All of these individuals participated in one of 11 focus group discussions conducted between February and April 2016. Seven of these young people had first been interviewed during individual exploratory interviews conducted in October 2015. Exploratory interviews were conducted in French. Focus group discussions were conducted by Souleymane Sow, third author of this paper, in some cases with participation of Alice Desclaux in French and the three main languages of Guinea (Soussou, Pular, Malinké) facilitated by focus group leaders that also acted as translators. Kelley Sams and Alice Desclaux, the two first co-authors of this paper both contributed to the analysis of the qualitative data for themes and the write-up of findings. Alice Desclaux was co-responsible for the social science component of the study and involved in Ebola response and preparedness in Guinea since 2014.

The average age of individuals interviewed for this study was 22 years old (ranging from 16 to 29). Slightly more women (22/40) than men were interviewed, and the majority identified as being ethnically Soussou (22), followed by Malinké (10), Fulani (3), and Kissi (2), with three identifying as other ethnicities (Guerzé, etc.). Almost all (36/40) respondents were Muslim, and reported diverse professional profiles ranging from being students (17), having graduated but currently unemployed (7), craftsmen or laborers (8), sales (4) or employed (4). The average time spent hospitalized in ETUs was 14 days (7–30) between July 2014 and August 2015 (6–18 months before focus group discussions took place).

Interviews and focus group discussions were recorded and transcribed. Sections in local languages were translated to French following transcription. After the data were cleaned, they were uploaded into the online qualitative data analysis application Dedoose and coded for conceptual categories using a grounded theory approach (Ralph, Birks and Chapman 2015). Kelley Sams translated the citations used here from French to English during the writing of this article. To assure confidentiality, all names mentioned in this article are pseudonyms chosen to reflect the ethnic origin and gender of participants.

The exploratory interviews conducted at the beginning of this study were not very rich in information, mainly resulting in short and closed impersonal responses. The stigma faced by Ebola survivors in Guinea also contributed to the hesitancy of respondents when being interviewed during exploratory interviews. This highlighted the need to establish a relationship of trust with respondents as well as in-depth knowledge of the social context with long-term fieldwork, something that was done before conducting the second 'mini'

focus group discussions. These focus groups consisted of three to five participants with three to four focus group leaders/translators similar in age to respondents who often knew each other from the clinic or socialized outside the discussion sessions. Most of these leaders were Guinean and spoke the same languages as discussion participants. These facilitators were recruited due to their previous involvement with Ebola response efforts and were usually familiar with the participants in the groups that they led. They were trained in encouraging open discussions and creating a safe judgment-free environment. Discussion leaders helped respondents feel comfortable discussing issues around their experiences before, during, and after treatment for Ebola. These discussions, which lasted an average of two hours each, did not have a predefined order and allowed for open discussion, even for those who were speaking publicly for the first time about their experience in the ETUs.

Participants were recruited from the Postebogui Project, a multi-site prospective study that provides free access to care for Ebola survivors and studies the clinical, psychological, and socio-anthropological effects of the disease. The socio-anthropological study, as well as the overall study, are implemented by Guinean, West African, and French institutional partners. IRB approval was granted by the French National Institute of Health and Medical Research (*Institut National de la Santé et de la Recherche Médicale* [INSERM]) and ethical approval by the Guinean *Comité National d’Ethique pour la Recherche en Santé*. The clinic where discussions took place provided a secure and respectful environment for participants, largely due to the friendly attitude of peer Ebola survivors counselors; moreover, it was a place where participants regularly met, socialized, and could speak about their common experience, something rarely possible in their everyday environments.

## **Ebola treatment units and medications**

At the end of March 2014, immediately following the World Health Organization’s declaration of an Ebola virus epidemic in Guinea, two treatment centers (ETU) were opened with the support of *Médecins sans Frontières* (MSF). One located in Macenta (Guinée Forestière), near the center of the epidemic, and one at the Donka University Hospital in Conakry. At the beginning of 2015, an additional 13 centers were functioning in the country, which also included transit centers for suspected cases and a center for exposed health care workers (Centre de Traitement des Soignants, CTS). At the end of 2015, two ETU opened up in the Conakry area: Coyah, and Nongo. These two centers took over the role previously held by Donka hospital of providing Ebola services for the capital city.

Although these centers were physically separated from the broader community, the barriers that marked this separation were intentionally able to be seen through, usually made with a light mesh material, in order to show transparency and encourage trust. Most of the participants in this research were hospitalized at Donka ETU, but several were also treated at other centers in Conakry (Nongo, Coyah, CTS). These individuals either came on their own to treatment centers or were taken by Ebola response vehicles. Almost all of these young people came in after they had lost a family member from Ebola, and many entered treatment facilities with other members of their family. Some respondents reported being unresponsive or showing serious symptoms at the time that they were admitted to the treatment center, but most had few symptoms, usually limited to acute tiredness and fever.

After testing incoming patients for the disease, treatment centers usually provided patients with oral rehydration solution, antibiotics and antipyretics. These treatments were

complemented by medicines to address specific symptoms such as diarrhea or vomiting, as well as vitamins and micro-nutrients. Patients also received meals, mineral water and juice, and nutritional supplements similar to Plumpy'Nut. Some respondents also received favipiravir, an experimental anti-viral drug, or convalescent plasma, that were tested during clinical trials in 2014–2015. For the purpose of this article, a broad definition of 'treatment' is used to include any of these substances given by the treatment centers to improve the health of patients with Ebola virus disease.

## Findings

Focus group discussions revealed that most respondents had heard, either before entering the treatment center or from phone calls from friends/family after being admitted, that the Ebola response was intentionally killing patients with the medications it provided. Telephone communication during patients' stays in the treatment centers had contradictory effects on refusal of medication at the treatment centers: most family members would call repeatedly to urge patients to refuse all types of medication offered at the center and reinforce fear of the medication, but some encouraged them to comply and accept treatment.

### Refusal

Most of the young adults that were interviewed reported initially refusing to consume any sort of treatment or medication given at the center. These refusals took different forms and were explained in diverse ways. Some respondents reported overtly rejecting treatments, but more often, treatments were accepted from treatment center staff, and respondents pretended to consume the products before throwing them away. For example, Idrissa (male, 20, mechanic) explained that during his first day at the treatment center he rejected treatment, but when forced to accept the medications, he quickly got rid of them.

As for me, the same day that I came, I refused to take the medication. They said to put an IV drip in me, I said no. I held my ground, and then they had to throw themselves on me. Even that black medication...when they gave that to me too, I threw it away.

Along with simply disposing of the medication, there was a certain trickery implied in not consuming these treatments. Following Idrissa's description of his experience, Adama (male, 21, mason) adds that 'There were other [patients] who would take the medicines in their hand and as soon as the doctor turned his back, they would throw them under the bed and say that they had taken them.'

Other respondents reported demanding to see the containers that the medications came in, or carefully examining the products that they were given, in order to be certain of what they were being asked to take. Aissatou (female, 25, unemployed), who holds a bachelor's degree in biology/quality control, reported having questioned the health care workers at the center about the medications that she was given, in order to have information concerning what these really were.

The doctors came. They gave me the medicine and I said 'No, I'm not going to take that one, call your supervisor.' 'Really? But why, miss?' I said, 'No. Call your boss.' And, since everyone was so nice there, the supervisor came to see me: 'My wife [friendly joke based on their ethnic

relationship]! I'm here, what's wrong?' I said, 'Mr., they are telling me to take these medicines, but I'm not going to take them because I don't know what they are.' He said 'Well, it's paracetamol, metro [metronidazole, an antibiotic commonly used to treat diarrhea], and those types of things...' I said, 'Where is it written 'paracetamol, metro'? Because they only gave me the pills. Nothing is written on them. Give me the package, I want to read it.'

Building off Aissatou's experience, Adama added 'In fact, personally, when I was admitted, I did the experiment of pretending to sleep to see what they were giving to other patients, but I saw that it was pills and Orasel [oral rehydration solution].'

Aminatou (female, 22, degree in telecommunications, unemployed) was so afraid of being poisoned by products distributed by the Ebola response staff that she tried to hide her fever in order to avoid being given medication.

Every morning the Red Cross came to 'flash' [measure temperature using an infrared forehead thermometer] us, but every time, before they came, my body would get hot. But I was so scared because I had heard that they killed people and that they do all sorts of things, so every morning before they came, I drank frozen juice, and when they flashed me, my temperature was always normal, but as soon as they left, a few minutes later, my body would get hot again.

In addition to refusing medication, some patients also declined food that was offered to them at the centers. Contact with family and friends from outside the treatment centers encouraged this rejection.

There was a blackish product there that they gave us. When I took it from them, I threw it on the ground because no doctors were watching me. After I pretended to take it but instead threw it out, then I refused to accept it. During that time, people from back home called to say to not take any medications because if we took them we would die. They [treatment center personnel] sent us food to eat, but we refused that as well. Zenab (female, 22, housekeeper).

### *Why refuse?*

Refusal of treatment seemed to primarily be motivated by three factors: (1) fear of being poisoned by treatment center staff; (2) experience of knowing someone who died after consuming medication at the center; (3) lack of hope or desire to recover from the illness. Most often, these hesitations reflected public opinion that considered treatment centers as places of death rather than healing. Baba (male, 25, degree in mathematics and digital business management, unemployed) like many respondents, reported having the idea that treatment centers were dangerous places well before being admitted.

When we came to the ETU the 13th, we saw some people outside. At that time, they said that when you enter there, they'll inject you and you'll die...

*Interviewer:* Who was saying that?

Baba: People! It was like a slogan during that time in Conakry.

Death was not seen as simply related to therapeutic failure, but as being caused intentionally by treatment center staff.

We were really scared, we had it in our heads that we wouldn't get past a certain point either, because we had it in our minds that Ebola kills. People said that when you arrive there, the doctors give you a shot and even if you don't have Ebola, they say that you have Ebola just to kill you. Bafodé (male, 18, student).



In addition to this persecutory interpretation, respondents used empirical evidence to construct perceptions about the cause and effect relationship between medications and death without directly blaming the intentions of the Ebola response. Sita (female, 18, student), explained that she had witnessed the death of her mother immediately after having consumed a medication at the center and was afraid that the same thing would happen to her.

Afterwards, they gave me another medication because my body was hot, but I said that I was afraid to take this product because when my mother died, she took something, and then she passed away. So as soon as I took their product, right away, I knew I was going to die too. My little sister had already begun to cry.

Sometimes, respondents used empirical evidence of the causal relationship between medication and death to highlight the malicious intentions of the treatment center staff:

*Interviewer:* You thought that they were the ones killing people?

*Sabana (female, 18, student):* Oh! My brother, with all the deaths there, those ideas go through your mind...

*Hawa (female, 22, hairdresser):* When I heard the news, I automatically thought of what they were saying in the neighborhood 'if you go, they will inject you', so I said to myself that it would probably be my dead body that my parents would come pick-up. This thought came to me automatically, but I give thanks to God that I went there and I came back [alive].

Other people expressed a more general fear of dying, without differentiating the role of the illness from that of the treatments. Saran (female, 18, student) explained that she was afraid of both Ebola virus disease and the medications given out at the center.

*Saran:* Oh! I thought I was going to die because I heard people say that once someone is infected, they can't recover.

*Interviewer:* Did the doctors give you the medication?

*Saran:* Yes! They gave me the medicines, even at night, but I didn't take all of them.

*Interviewer:* Why didn't you take them?

*Saran:* Because I was scared.

In addition, some individuals reported having refused treatment after losing hope of surviving, often following the death of close family members. For Ismael (male, 22, driver), life was not worth living after losing most of his immediate family.

So I said that it would be better if I died too. When they sent me food to eat, I didn't eat it, and even when they gave me medicines, I put them under my pillow. When the doctors would come, they gave me medicine, I refused to take them, I said that I took them and then I would put them under the mattress, I did not take them, because I said to myself that now that my mother is dead, my father is dead, my big brothers and sisters are dead [...] 27 people died in our family, so I wanted to die too.

Practices of explicit or hidden refusal reported by young Ebola survivors showed a general feeling of distrust that began even before entering the treatment center. However, collective representations related to intentional poisoning were not the only factors influencing rejection of treatment. This noncompliance also resulted from the hopelessness and trauma caused by the epidemic as well as treatment as a cause of death. For the survivors that we interviewed, these perceptions and attitudes changed over the course of hospitalization.

### ***Factors influencing non-compliance at treatment centers***

At the treatment centers, attitudes toward medications were influenced by relationships with other patients as well through contact with family and friends from home.

#### ***Transmission of reticence***

Reticence was first constructed based on public opinion and representations that patients were exposed to before coming into treatment centers. Patients who kept their telephones received calls 'from outside' that fed into fears about medications at the center. Malick (male, 19, student) explained that he had been warned about the dangers of the treatment center before being admitted, and that his family continued to share these warnings after he was hospitalized.

The day when I left for the ETU, I was coming back from the field, people said they were going to kill me, that if you drank their water and ate their food, you would all die. And even when I was at the ETU, certain family members called me to say that they [treatment center staff] were going to kill us there.

Several respondents reported being very uncomfortable with contradictions between their families' desires and the advice of health care providers at treatment centers.

One of my stepmothers told me, 'Don't drink the water, if you drink the water you'll die'. But I didn't listen to them. I drank the water there; I just drank water. All I did was drink water. N'Gaballou (female, 20, salesperson).

These calls caused some respondents to become worried about maintaining contact with their families. Some even went so far as to refuse to take any calls or to cut off contact from friends and family that also severed important links of support. As Adama described, he decided that the calls he received were causing more harm than good.

When you are in there, the only problem is that people call you to tell you 'Don't take the medicine, don't accept this or that'. If you believe them, you'll die, because they call to discourage you from accepting the injections or other things. Me, personally, the same day that I was admitted, there was a friend who called me. I answered thinking that he was calling to say hello. He asked me 'Where are you?' I told him that I was at the ETU. Then he started to tell me not to accept the IV drip or the medicines, so I told him not to call me anymore if it was just to say not to take something, instead of to say that he hoped I recovered soon. So I turned off my phone until I was released because I said to myself that if I followed his advice, it would kill me.

#### ***Social configurations of doubt or trust***

Relationships between patients at the treatment centers also fed into suspicions related to the effects of medication, particularly following the numerous deaths that occurred at the centers. Health care workers often chose not to announce deaths to avoid additional fear, sadness or discouragement. However, this secrecy contributed to fears that treatment centers were using medications to intentionally kill patients. Sita explains that when she did not see her brother for a few days in the treatment center she thought his disappearance might be linked to the medication that he was given.

Because we didn't see our big brother, [we asked ourselves] did they kill him? You know, we were worried too, so for three days we were tormented. We became dominated by the illness, now we didn't walk anymore; at night all we did was cry, when I cried my little sister cried

too. Afterwards, they came to tell us not to worry or our temperatures would go up... I said to myself that they didn't kill our big brother. When they came in our room, they asked us to take the medicines, but we wouldn't accept them, [we thought] that our big brother took these products and that's why he was gone now.

However, patients sometimes developed trust in medications by watching the medications' effects on others. Michael (male, 25, health technician) explained how his friend finally agreed to take the medication after seeing that it had no negative effect on him.

They picked me up at Forécariah, they brought me to the ETU here, I followed the treatment. The first day, my friend who I was with, he was very discouraged about the medication. And me, myself, before I left, they said whatever they give you there [at the treatment center], don't take it. If the Whites brought the medicines, I looked at the medicines, but still... I said "These, these are good medicines". My friend there, he watched me first, I had to finish taking them, 15–30 min, like that, and he'd take them too, if there were no reaction in me.

Despite messages transmitted from the 'outside' to patients in treatment centers, or experiences witnessing the effects of the treatments on fellow patients that confirmed or challenged suspicions, perceptions changed over time. Patients experienced a reality of life in the treatment centers that was very different from what was described to them before being admitted. These experiences, as well as the encouragement of health care workers, helped patients counter public suspicion of the centers and encourage uptake of treatments at the centers.

### **Factors encouraging compliance**

After several days, most patients surpassed their initial reticence, encouraged by health care workers and other patients at the centers, as well as by their own individual experiences.

### **Discourse and strategies of health care workers**

Respondents who were hospitalized at the beginning of the epidemic reported that treatment center staff tried to reason with patients to encourage treatment uptake. As time went on, health care workers began to systematically 'brief' all patients about the importance of treatment as soon as they were admitted to the centers.

*Binta (female, 18, student):* When it was time to take the medicine: morning, midday, evening, you also took it at midnight and 4 am. If you said that you didn't want to take the medicine, they reassured you, coaxed you, they didn't force you, but they used all of the ways that they could get you to accept, and even if you insulted them, they wouldn't say anything.

The arguments of health care workers were particularly convincing when they provided patients with general care and assured good meals and conditions at the centers. Idrissa, who refused all medications when first hospitalized, was greatly reassured by treatment center staff who convinced him that they did not want to cause any harm.

The doctors took really good care of us. They educated us and told us not to believe what people in the neighborhoods were saying. They didn't kill anyone. They couldn't kill anyone, except those to whom God did not grant a long life.

Certain health care providers became personally very committed to convincing patients to take their medications, even going so far as to take the medications themselves in front of these suspicious patients. Aissatou described how she began to feel comfortable taking the same medication that a health care worker took in front of her.

The doctor told me ‘Ok, if I take one pill from each of these products, will you take them too?’ ‘Ok, take all of them,’ I answered. He took all of them and he told me ‘You see? I took them.’ He opened his mouth to show me. I said ‘Ok, give them to me too.’ So I noticed which were the four he took [*laughing*]. I kept my eye out for those four products that the doctor took, then every morning, when they would come, if they give me those, I would take them.

Some health care workers took the time to establish close relationships with patients, making jokes based on ethnic identity and providing personal attention and friendship that helped establish trust. According to Zenab, these relationships were what made her feel comfortable accepting the medication given by the treatment center.

In the morning, the doctors all came to see us. They gave us advice; they told us to take the medicine because ‘We don’t kill here. What the people say in the neighborhoods and what actually goes on here is not the same thing.’ And it’s true, we saw it ourselves. It’s not the same thing at all because they took really good care of us. Whatever you wanted, they would give you. Whatever we asked them to do for us, when we put on our *pagne* [*clothes*] for the day, at night they would come change it for us. The meals that we asked for, that’s what they would send us, they gave us everything. After that, when they sent the medicine in the morning, we took it.

Patients were not only convinced by the professional education strategies mobilized by caregivers, but more importantly through personal relationships that developed at the treatment centers. Respondents described being generally treated very well: whether through the food they were given, or medical care, or how they were treated on a personal level.

### *The role of experience*

Many respondents described refusing treatment during their first few days of hospitalization. This rejection was usually abandoned after several days. Certain former patients saw their recovery as directly related to their change in position toward public opinion about treatment centers or the appropriate strategy for recovery. Adama explained that he decided to take the medicine from the center after testing how he felt when he did not take the medication.

Since my sister, who I was with, died over there [...] since she was a [traveling] salesperson, she walked a lot [in the neighborhoods] and because of that, she heard a lot of things. When she came, one day she said to me, ‘I am not going to take those medicines there,’ I said, ‘Oh, really!’ After she said that, I also went two days without taking the medication, but when I noticed that my health wasn’t getting any better and the others were taking the medications without any problem, I said that I should see [...] So I started to take the medicine and drink and eat well and I started to feel better.

Patients shared their experiences with one another during the abundance of ‘down-time’ that they had at the treatment centers. Recommendations about medications circulated between patients within treatment centers, especially from more experienced to new patients. The discourse of these more experienced patients was similar to that disseminated by health care workers, but rather than a discourse of authority it was transformed to a discourse of experience.

Those who had already overcome the acute phase of Ebola and were still hospitalized shared their experiences with newly admitted patients and provided encouragement. The advice of these ‘old-timers’ was inscribed in relationships of protection and solidarity, especially with younger patients. Idrissa explained how he was encouraged to comply with treatment protocol by employees of the treatment center, and in turn, he also encouraged other patients,

Fanta [an ETU employee] who was there, used to give me a lot of advice. She told me not to listen to what people said, and especially not to worry, that I was going to get better and go home, just to eat well, take my medicine, and drink a lot of water. And the newcomers there, we were the ones who encouraged them. We just told them to eat well, take their medicine, and especially to drink a lot to have strength.

Building trust in the products distributed by the center occurred through direct visual and experiential knowledge as well as from verbal messages.

*Interviewer:* When you had just arrived, did you take the products [medications]?

*Sita:* No, because my mother had just died. But because of the encouragement of my friend’s big brother I started to take the products. He took the medicines in front of me and this reassured me.

Treatment compliance seems to have depended on factors that were much broader than information transmitted by health care workers that did not particularly emphasize the pharmacological efficacy of the products.

## Discussion

Most of the young Ebola survivors whom we interviewed rejected treatment during their first few days of hospitalization. These refusals were explained as being due to concerns about poisoning or because respondents knew of other patients who died following treatment and attributed these deaths to the medications rather than the disease. Like many anthropological studies involving ETUs, our research faced challenges posed by the lack of observational data due to difficulty accessing care spaces during the outbreak (Brown and Kelly 2014). Collecting in-depth information from survivors was also difficult in the Guinean context; participants’ trust in the research team was developed slowly related to care services offered to them, and through the gradual adaptation of our data collection method through a time-consuming process. The efforts of our research team helped creating conditions for participants’ confidence and sincerity, which is perceptible in the quality of our dataset. One acknowledged limitation of this research is that we do not have data from patients who died at the ETU, who may have never changed from a position of refusal of medication toward compliance. Since treatment of Ebola Virus Disease was done through interventions to improve nutritional status, address dehydration and treat symptoms such as fever and vomiting, noncompliance could have had serious consequences for Ebola patients and reduce survival rates.

The rejection of treatment could have also contributed to the disappointing results of the JIKI vaccine trial (Nguyen et al., 2017) that showed weak plasma concentrations on Day 2 and 4 of the experimental drug favipiravir in research participants in Guinea. In their article, the authors indicate that conditions such as dehydration, diarrhea or vomiting could have been responsible for the lower-than-predicated concentrations. While study coordinators presumed compliance with study medications, we may wonder if the

participants of this trial, conducted in one of the ETUs where our study participants were treated, had consumed the treatments offered to them in the same way as the patients we interviewed.

From a theoretical perspective, our results show the relevance to ETUs of Street and Coleman's (2012) conceptual approach of hospital spaces as heterotopia, i.e. imagined spaces with multilayered meanings and cohabitation of biomedical and lay logics, in spite of their organization being based on biosecurity norms and biomedical care imperatives. Within these bounded spaces, information and communication technologies such as cellphones may bring fully contradictory messages as part of family domestic care, opening perspectives for the study of care at a distance. The production of trust inside ETUs by health workers' engagement and quality care may be another aspect of this heterotopia through producing hope for patients dominated by fear. New questions arise about the possible emergence of hope and trust from ETU spaces, and its extension to other health services in a long lasting way.

Resistance in different sub-Saharan African countries against mass-treatment programs for other diseases has been attributed to fear of side-effects, discordance between biomedical and popular perceptions of disease, and 'insufficient' health education (Parker, Allen and Hastings 2008). In our study, participants did not complain about the specific pharmaceutical effects of medicines and most of them did not even enquire about the nature of treatments that they would refuse whatever their supposed composition. This observation could be related to the education level of participants; however, many students and college graduates were among those who refused. As Richards (2016) describes in Sierra Leone, the success of Ebola interventions in controlling the spread of the virus is largely dependent on the population's negotiation with and relationship to these interventions, rather than on science-based knowledge issues. In several interviews, study participants with high educational levels emphasized the role of political leaders and multinational companies in consciously facilitating the diffusion of Ebola. They also mentioned that the virus was created by 'white scientists,' following global conspiracy theories that have been developing in West Africa during last two decades particularly among educated youth (Dozon 2017). These observations show the need to address social representations, beyond favoring science-based and community-based knowledge promotion (Richards 2016).

In their review of the underlying factors that contributed to resistance towards the Ebola response in Guinea and Sierra Leone, Wilkinson and Fairhead (2017) conclude that aggressive responses to disease interventions cannot be considered through 'single-variable non-compliance'. For these authors, resistance was related to the particular political context beyond the specific disease and its response interventions. Authoritarian and sometimes violent application of public health measures such as contact case identification, isolation and cantonment, particularly in rural areas where full villages were encircled and isolated, fed fears of the population towards the Ebola response (Desclaux, Diop and Doyon 2017). The political and ethical concerns lead to disease interventions such as household spraying done by the Red Cross to be misread by populations as an intentional strategy to eliminate minority and rural populations (Wilkinson and Fairhead 2017). The ACAPS, an international organization that analyzes strategic information for UN agencies and NGOs, created a framework for recording resistance that became a database for the three countries the most affected by the West African Ebola epidemic (ACAPS 2015). Their work highlights resistance against agents working with Ebola response and provides a quantitative analysis of the frequency and severity of incidents but did not examine treatment refusal at ETU. These findings show

that incidents declined in both frequency and severity as education and information campaigns were rolled out in affected areas, including testimonies of survivors that explained the care work performed in ETUs. Our data do not allow us to specifically analyze the difference in refusal for patients admitted during different periods of the outbreak, but they do suggest that distrust of treatment became less in the latter part of the epidemic (after December 2014), when more ETUs were open and patients' conditions of care improved, corresponding with the overall reduction in resistance to the Ebola response (ACAPS 2015).

ACAPS' approach, as well as that of Wilkinson and Fairhead, prioritizes how macro-social factors create politics of resistance. The formation of resistance patterns cannot be considered without moving beyond the theoretical analysis of ETUs as 'places apart' specifically governed by biomedical culture, as previously described in hospital ethnography, towards considering their simultaneously bounded and permeable status (Street and Coleman 2012).

Family advice is part of the long-studied role of caregivers in 'therapy management' in African pluralistic therapeutic landscapes (Janzen 1982). In contemporary West Africa, family bonds underlie many aspects of young adults' lives, particularly regarding health (Lipton 2017). Family advice, though actually reducing patients' chances to recover, were similar to the provision of food, body care, spiritual and relational support that usually contribute to making hospital wards domestic care spaces as well as biomedical ones (Brown 2012). Unlike other wards in African hospitals where caregivers are transferred material care tasks by health workers, families' and friends' physical presence in ETUs was forbidden for biosecurity reasons. It led them to provide advices and support on the phone, a twenty-first century form of remote care based on information and communication technologies, increasingly documented for domestic care as well as telemedicine (Ahlin 2018). Hospitalized individuals often protected themselves from this ambiguous 'domestic care' in ETUs by switching off mobile phones or refusing contact with family and friends trying to relay messages that went against those being given through the biomedical system.

Both more experienced patients and health care providers played an important role in building the trust of newly hospitalized patients (Fribault, Taverne and Desclaux 2016). The empathetic attitudes described by patients and documented in other ETU settings contrasts with attitudes among health professionals confronted with Ebola outside ETUs, attitudes often dominated by fear (Hofman and Au 2017). In spite of difficulty establishing relationships under the restriction posed by wearing Personal Protective Equipment, compassionate attitudes also contrast with the inhospitality often seen in health services related to other ailments, when care is not provided without payment first (Jaffré and Olivier de Sardan 2003). Additional ethnographic analysis is needed to understand the social construction of compassion in ETUs and its relationship with high level accessible and patient-centered models of care, particularly from the health care workers perspective, as mentioned in other contexts (Abramowitz 2017); the long-term impact of this experience on the relationships between the Guinean population and their health system after the withdrawal of ETUs and their patient-centered model of care should be also studied.

## Conclusions

The resistance to treatment in ETUs revealed by the carefully adapted methodology, and the contextual and intentional trust-building approach of our study, has not been documented in response to other illnesses. While analyzing the factors related to deaths within

ETUs is beyond the scope of this project, refusal of treatment most likely contributed to the negative health outcomes in many of these cases and should be under scrutiny in clinical research on antiviral efficacy, along with pharmaceutical aspects. Also, the consequences of defiance towards ETUs and treatment, either in terms of missed care opportunities or delayed admission, or in psychological impact for patients of fear of being poisoned by the people supposed to be providing care and of contradiction between biomedical and family advice, should be evaluated further in public health and psychosocial studies.

Data presented here show that the rejection of treatment during hospitalization was in continuity with acts of resistance seen during the epidemic, influenced by broader factors (ACAPS 2015; Fribault 2015; Wilkinson and Fairhead 2017). Because the 'victims' of non-compliance are Ebola patients themselves and not health care workers targeted by 'reticence', this was less visible and provoked less of a reaction from the global health community. The findings of this study highlight the social construction of frameworks of resistance by the population that cast a shadow on patients hospitalized for Ebola, both surviving and deceased. Studying the attitudes of a population faced with an epidemic should include both an examination of patient resistance to treatment, as well as relationships with disease response outside of medical facilities.

Consideration of the acceptability of medications used in Ebola treatment centers was virtually absent during the West-African epidemic, where response was focused on providing efficient services as quickly as possible. Instead, public debates focused on the ethical issues around the types and quality of treatments that should be given in ETUs and the inequities in treatment provision under external constraints (Hoffman and Au 2017). Since 2015, vaccine trials concentrated studies on acceptability and community engagement, and they seem to be spaces where trust and collaboration in fighting the virus may be produced, owing to resources and conceptual input in support measures (Enria et al. 2016). Findings of this research highlight the need to reflect upon the social acceptability of other treatments, such as those tested and used in Congo Democratic Republic in 2018–2019, at micro and macro-social levels, i.e. in local configurations of patient-family-health workers relationships in ETUs and in the different political and historical contexts of the outbreak sites.

## Note

1. Postebogui Research Project: [Re]vivre après Ebola en Guinée, TransVIHMI (IRD, INSERM, Montpellier University), CERFIG – Donka University Hospital, Gamal Nasser University.

## Ethical approval

Ethical approval n° 015/CERS/15 obtained from Comité National d'Ethique pour la Recherche en Santé de Guinée on February 15, 2015.

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