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'We will soon be dead': stigma and cascades of looping effects in a collaborative Ebola vaccine trial

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ABSTRACT

Can the careful implementation of global health research reduce the stigmatization of involved human subjects? This study analyses stigma in an Ebola vaccine clinical trial in West Africa that deployed complex community engagement strategies including a sensitization component. Qualitative research found that stigma against trial subjects manifested in various forms beyond the reach of these anti-stigma interventions. Drawing on and advancing Hacking's notion of 'looping effects', this paper argues that stigma was a product of a wider socio-historical context beyond the control of community-based interventions. This case prompts global health practitioners to think through the limitations of community-based interventions in practice.

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Introduction

Joseph, a 27-year-old barber, took part in a clinical trial testing a new Ebola vaccine in Liberia in early 2015. He participated in the trial because he wanted to get some money, food, and healthcare – all scarce in Monrovia's suburbs. A year and a half later, in September 2016, Joseph introduced us (the researcher and assistant) to his friends who also took part in the trial. They agreed to take part in a focus group discussion (FGD), and proposed we talk outside a house where one of them lived. Several onlookers from the neighbourhood gathered around us. We began by asking the focus group participants: 'Can you tell us about Ebola vaccine research?' Joseph was about to start talking, but an onlooker interrupted him, saying: 'Ebola can be passed on from one person to another by you holding an infected person'. Joseph replied: 'Brother, please don't disturb us because you didn't participate in the vaccination process. We took the vaccine and you didn't'. The observer became immediately concerned, asking, 'Did you take the vaccine?' 'Yes', Joseph replied with confidence. 'But you guys will soon be dead!' said the onlooker and then quickly walked away. 'Did you hear what he said?', Joseph asked us, repeating, "'we will soon be dead'". This is what we have been hearing since we took the vaccine; sometimes we get even afraid to sleep; thinking that we won't get up the next morning. ... We receive a lot of deadly words from people due to our participation in the vaccination process'.

This paper shows that context and socially embedded knowledge matter when it comes to the implementation and evaluation of global health interventions. In 2014, several clinical trials were launched in West Africa to test vaccines against Ebola Virus Disease. Following recommendations made by the World Health Organization, the United States Agency for International Development, and the National Institutes of Health, to name a few, Ebola research teams in West Africa developed complex engagement and mobilization strategies that would make their research more community and participant centred. As part of collaboration between the US and Liberian governments, more

than 100 Liberians were employed to establish culturally sensitive communications, advocacy and community engagement, deemed essential to the protection of human subjects. Official reports about the trial (Doe-Anderson et al., 2016; Kennedy et al., 2016) provide thick description of the collaborative component, including changes to participant recruitment and other adjustments that research teams made. Doe-Anderson and colleagues note that stigma remained a challenge:

There was still a degree of stigma and discrimination associated with participation in the vaccine trial, as some members of the community believed that participants were being vaccinated with the Ebola virus and would eventually infect others in the community (Doe-Anderson et al., 2016).

At that time when Ebola research was launched in Liberia, numerous rumours were proliferating that Ebola was not real, that Ebola was a man-made disease designed to kill Africans, that the government had created the Ebola scheme to attract international funding. President Ellen Johnson Sirleaf was identified with the Queen of Sheba – a reincarnated woman from the netherworld thirsty for blood to boost her powers (Epstein, 2015; Perry & Sayndee, 2016). Significantly, the outbreak hit Liberia on its difficult path of recovery from more than 10 years of the civil war, and the absence of the most fundamental public health and state capacities has fuelled the devastation (Wilkinson & Leach, 2015). The internationally led response across West Africa was generally marked by culturally insensitive patterns of communication: local health systems and public infrastructures were neglected, and peoples' concerns and priorities were not always taken seriously (e.g. Chandler et al., 2015; Jones, 2014; Wilkinson et al., 2017). A heavily militarized approach to establishing quarantine zones in poor areas of Monrovia approached vulnerable citizens as loci of Ebola-related issues, which fuelled fears and mistrust about healthcare workers and carried interventions (Benton, 2017; Hoffman, 2016).

Ebola-related anxieties and conspiracies were extended to the trial and its collaborative component. To respond to stigma, rumours, and myths, the clinical trial included collaborative activities undertaken by Liberians, such as counselling participants and their families. Community-engagement teams organized mobile units and discussion forums to disseminate information about the trial in various communities. Because the word 'trial' raised suspicions and questions for some, information-provision was adjusted and the term 'vaccine study' was used instead of 'vaccine trial'. Encouraging mass media coverage of Ebola research programmes and establishing an Ebola hotline, researchers actively worked to resolve misconceptions and confusions about the trial. Informed consent procedures were led by Liberian trial educators who provided participants with information about Ebola and Ebola vaccine research groups, which were followed by individual face-to-face sessions to discuss the trial and its risks, and obtain meaningful informed consent. Independent news reporters were provided with training in scientific literacy and enhanced understanding of trial procedures in order to avoid reporting biases. Community mobilization teams trained some Liberians as so-called trackers, employed by research teams to address participants' questions, concerns, and complaints. Trackers were hired to follow participants, collect and minimize rumours through advocacy, and counter stigma. Collaborative partnerships also involved close work with traditional leaders and artists, some of whom created and promoted songs about collaboration with Ebola research. As a result, the trial was able to beat the odds and rapidly recruit 1500 people with 98% compliance rates (Doe-Anderson et al., 2016; Kennedy et al., 2016).

Nonetheless, as the opening story illustrates, people who had participated in the trial still faced negative appraisals by their neighbours one year after the trial ended. In terms of classic sociological theory on stigma, the identities of the trial subjects were 'spoiled', resulting in a range of negative outcomes for people marked by their participation in the research (Goffman, 1963). This indicated that the very stigma that the researchers conducting the trial wanted to avoid was persistent.

Why were trial subjects still stigmatized? In recent years, there has been a growing interest in structural factors that reinforce stigma, as an attempt to explain why stigma often persists in the presence of anti-stigma interventions (Hatzenbuehler, 2016; Parker & Aggleton, 2003). Power differences, poverty, and a lack of social and economic capital often fuel stigma and discrimination

(Bos et al., 2013). What this literature suggests is that it is important to consider stigma as a dynamic and interactive social process existing beyond narrowly defined categories. Stereotyping is one of the complex dimensions of stigma in which stigmatizers produce negative generalizations about the stigmatized. Hacking's (1991, 2007) work on 'looping effects' provides insights into this process. A key analytic point in Hacking's work is that different 'kinds' of humans, such as 'trial subjects', do not appear out of nowhere but are made up in unique socio-historical settings in which specific and often stereotypical information is attributed to them as people subjected to a new classification. As a result, such people are constantly targeted by various kinds of socially embedded knowledge; they thus are 'moving targets' who must react to being classified, whether they accept or resist it.

Hacking calls this process 'dynamic nominalism' and shows how it works in practice: institutions, social contexts, and socially embedded knowledge produce various kinds of looping effects. With this framework, we can see how social stigma, as generalizations about human kinds, can be conceptualized as examples of looping effects (Matthews, Dwyer, & Snoek, 2017). Recently, anthropologists have employed the concept of dynamic nominalism to show how biomedical interventions shape social relations, enact new kinds of people in global health work, and proliferate disease taxonomies (Holt, 2013; Lock & Nguyen, 2010; Moyer & Nguyen, 2015). In relation to clinical trials, the making of 'vulnerable human subjects' can be seen as looping effects produced by biomedical institutions (Campbell & Stark, 2015). Moreover, randomized controlled trials are often surrounded by various less obvious looping effects produced by the contexts in which clinical trials are deployed (Adams, 2013).

As part of a growing academic interest in looping effects and in response to the call for more qualitative research on stigma (Kleinman & Hall-Clifford, 2009), this article analyses stigma against trial subjects in the Ebola vaccine trial. It invites us to think about stigma as cascades of proliferating looping effects targeting 'trial subjects' as an explanation of why stigmatization persists despite complex anti-stigmatization efforts.

Materials and methods

The study was conducted by the author and a skilled research assistant between August and December 2016, after the Ebola clinical trial officially ended. It included analysis of trial documents; interviews with researchers, former trial subjects, community members, and community leaders; as well as ethnographic research in the community that hosted the trial. More particularly, the article is based on information obtained from 25 former trial participants (referred to in this text as 'informants') through 11 face-to-face in-depth interviews and five focus-group discussions, which were conducted in English. Rumours about participation were collected during informal interactions with community members over the course of the three months of fieldwork. Other insights from this study are presented elsewhere (Alenichev et al., 2019; Alenichev & Nguyen, 2019).

The project was formally approved by the University of Amsterdam ethics board and the ethics board of the University of Liberia. The project was informally approved by community leaders and researchers. Informants were compensated with US\$2.50 for participating in an interview or focus group discussion, as required by the ethics board of the University of Liberia. All informants were legal adults (18 and older) living in the marginalized suburbs of Monrovia, which hosted the Ebola vaccine trial. For participants, it was important to remain anonymous, so we did not ask for in-depth demographic details during formal data collection sessions. A snowball-sampling strategy, starting in neighbourhoods near the research unit, was implemented. Written informed consent was obtained from each informant. The places and times for data collection were selected by participants. Audio recordings were then transcribed by a skilled local assistant. These sessions lasted 15–60 minutes, depending on informants' willingness to talk. The transcripts were systematized and then analysed thematically to identify stigmatizing patterns and attitudes.

Findings

Significantly, before the 2014 Ebola outbreak large-scale human subject research did not exist in Liberia. This meant that a 'trial subject' was a locally new kind of person that was being enacted through participation in a locally new kind of intervention. Various people seeking economic and healthcare benefits took on this new identity. Whilst research teams attributed objective and rational clinical discourses to 'trial subjects', those same people were attributed with negative information in their communities. Resulting in stigma and discrimination, such destabilizing looping effects led to the suffering of those who had received the vaccine, many of whom were already stigmatized for other reasons. In a focus group, an informant recalled: 'People were afraid of us; every one of us who participated in the vaccination process experienced the stigma. People were saying that we took the vaccine for money. Others said we shouldn't come around them. People were saying that we will die' (FGD 3).

This statement points to the analytic concern raised by this paper: Stigma was persistent in communities in parallel with a collaborative partnership and it affected numerous participants who were subjected to generalizations. In the following sections, I present ethnographic materials that hint at various looping effects that targeted 'protocol' trial subjects.

Trial subjects as targets

Informants explained that many people had wanted to participate in the trial. This resulted in a situation in which there were lines of people in front of the hospital where the vaccine was being administered. In one interview, an informant described how standing in line for the experimental vaccination worked to initiate stigmatization, as the potential subjects, supposedly anonymous, were instantly identified by people from their communities: 'People were looking at me in the line and they told me the vaccine was not good and I should leave the line' (Interview 1).

The lack of anonymity quickly became a problem. One informant explained that community members recognized people standing in line and then told others in their community about participants' trial enrolment:

[Researchers] say we should not feel bad [about stigma]. We used to be [in the line in front of the research unit] and some people's parents used to come and catch [people willing to take the vaccine] from the line, saying 'Don't take it'. Some people were there to carry your name [tell others in the community]. ... If your family is passing by [the research unit] and they see you [there], they will throw your things out of the house. As for me, my mother abandoned me for six months (FGD 5).

People who participated in the trial were met with divergent responses from those they knew. Some people were envious because the trial was a chance to earn some income. Others were worried for their welfare, and urged them not to participate because they might get sick from the trial. Gossip about participants extended to their friends and families, based on fears of disease contagion, unwillingness to be associated with a supposedly dying person, and suspicion that people partaking in research were engaged in Ebola businesses and conspiracies. Informants explained that the possibility of stigma was discussed during the informed consent process: '[Researchers] told us [stigma] was a risk that we are taking' (Interview 4). Trial subjects not only had to overcome this stigma but also the fear that perhaps the speculations about participants' risk of dying were true, as someone recalled in a focus group discussion: '[People from the community] were afraid to go and take [the vaccine] but we took ourselves, we went there to take it, we took risk saying: we are not afraid to die, and we went there, voluntarily' (FGD 2).

Some informants explained that some of their friends refused to participate due to fears of disease and rejection by others, even though they wanted the compensation for participation, food packages, access to healthcare, and other benefits. These were powerful motivations for those thinking of dropping out of the trial to reconsider. Informants' self-care included attempts to participate alone or in small groups, and to hide their participation, all the while hoping to receive long-lasting protection from the disease from researchers, who were seen as providers of a better

future. Informants were also aware of the possibility of being socially rejected before they began their participation, and hence they hid their participation as a form of self-care. This worked for some people, like this informant who said, ‘People [around me] didn’t know I took part in the vaccine so I didn’t experience any stigma’ (Interview 7).

Trial subjects as Ebola-infected people

It’s something like rumours that scientists came to our bush and started taking medicines putting it in chimpanzees that left here and other people went on and kill[ed] it [and] ate it. That is how the virus came and spread today (FGD 1).

In communities, Ebola-related rumours and conspiracies were layered upon gossip about trial subjects and the aims of the Ebola vaccine research project. A peculiar looping effect resulted as a result of common associations of the research unit with a conspiratorial nongovernmental organization, the vaccine with the injection of Ebola, and ‘trial subjects’ with ‘Ebola-infected people’. The idea that the Ebola vaccine contained Ebola quickly fuelled the fears of anyone affiliated with clinical research. People became afraid of those who had been vaccinated because they were thought to have the disease and to be able to spread it to others. One informant told us:

I knew [about stigma] because when we were in line, people started telling us that we are dead bodies because we don’t know that the vaccine has 5% Ebola in it. So I knew that when my family finds out they will feel bad and [it will be known] even at my job site (Interview 8).

In another interview, the informant recalled:

[Researchers] told us to stay away from anyone who is sick because the vaccine has 2% Ebola in it. After I took the vaccine my best friend started avoiding me and my family started to tell me that I want to bring the sickness in the house (Interview 2).

Overall, because of the stigma, trial subjects experienced something similar to what Ebola survivors experienced, as one of the informants explained:

There was the same stigma directed [at] vaccination participants. . . . It’s almost like we are Ebola survivors too because some of our friends die[d] instantly due to their participation in the vaccination process, but we who survive are not getting any benefit [like Ebola survivors]. They are receiving benefit by getting US\$300 every month; including rice and oil, which will run for five years before they stop receiving benefit (FGD 4).

Unlike Ebola survivors, whose suffering due to stigma was nationally and internationally addressed, the stigma that trial subjects bore was not similarly recognized, nor did they receive equal tangible benefits.

Trial subjects as people desperate enough to take ‘bad’ money

In the trial subjects’ communities, it was a common perception that informants took part in the research for money and affiliations with powerful institutions. There was an overall suspicion that Ebola-related activities were profitable, and that trial subjects were making money. One informant attested to this, saying: ‘In families, the notion was that the vaccine isn’t good due to the money they were giving along with the vaccine’ (FGD 3).

Local newspapers criticized research teams for ‘buying’ trial subjects, many of whom were marginalized, poor, and desperate. Trial subjects were seen as taking a risk of being voluntarily injected with a deadly vaccine for money, and thereby helping the transnational institutions that were sponsoring and conducting the trial. An informant explained:

At the time, there was a rumour again that when [researchers] were bringing [vaccines] people refused, because their belief was the World Health Organization was spreading this Ebola for them to make money. This was the reason many people refused [to participate in the trial] (FGD 1).

A common rumour portrayed Guinea, Liberia, and Sierra Leone as competing for the highest numbers of Ebola-related deaths, as it was imagined that the country that suffered the most would receive the highest amount of international aid. A peculiar rumour surrounded blood-donation practices, which were labelled as 'blood stealing' and 'blood businesses'. There was a bias in communities against anyone engaged in a collaboration or working with 'Ebola businesses', including healthcare officials, response teams, and trial participants. As a part of this, there was a marked bias against so-called reporters, meaning community members who reported Ebola-infected individuals to the authorities in hopes of receiving money for it. There were rumours that such reporters were poisoning wells with borax and then counting poisoned victims as Ebola deaths. One informant who took the Ebola vaccine told a story about his friend, a reporter, who eventually died from Ebola, leaving his family behind:

There were reporters who usually report the Ebola cases. I had a big brother who was a reporter during the Ebola crisis but he died leaving his family behind due to Ebola. ... Reporters were actually making money for each time they report[ed] cases during the Ebola crisis (FGD 3).

Due to the suspicion of Ebola businesses, anyone affiliated with anti-Ebola activities was not welcomed: researchers were seen as working for organizations spreading Ebola, participants were seen as taking a deadly compound for money, and reporters were seen as making money by counting sick people for nefarious organizations. One informant explained that they were also stigmatized by the research teams who, in their view, did not provide the support they had promised, and who did not respect the informants because they were marginalized:

In a proper way [research teams] weren't providing the care. ... They beg us to take the vaccine, but now they know that we have the virus in us. So they were not looking after us again. ... No more. So, when you go and talk for your own self headache, they will tell you: move from here. Harsh talks! At the hospital, the folks there can look at us like dogs. For me, you see me, I'm a *kpakpakpa* man. My head is not there (FGD 2).

Kpakpakpa is a colloquial Liberian-English term for hustling behaviour, operationalized as not necessarily virtuous ways of acquiring money through various sources. In Liberia, it is commonly associated with the activities of *zogos* – groups of young drug users living on the streets, involved in legal and illegal trade, many of whom are ex-combatants from Liberian civil wars and involved in criminal activities to provide for themselves (Tete, 2016). As one of the community members put it scathingly: 'These *zogos* have their own way. They do not listen to anyone, so most of them took the vaccine for the money to be able to buy their drugs, but those who have sense they won't take the vaccine. If researchers offer a vaccine shot for 40 USD, *zogos* will ask two for 80 USD'. Other negative narratives described trial subjects as 'CMB' (Cash Money Boys) or 'BM' (Bad Money): young individuals living on the street with limited access to formal employment. These individuals were imagined to be the main recipients of the vaccine: they always need money, they have experience with drugs in their bodies, and they are partially resistant to stigma as they experience it on an everyday basis.

Animals and monsters

In detailing the stigma, one informant recalled how community members mocked participants, saying they would turn into the biblical Goliath and monsters:

Rumours by people were spread that if you take [the vaccine] you will turn [in]to Goliath, monster, etc. And [they would say,] 'Don't come to this house again'. They are like: 'Don't even touch me. Now you and your own family can't even eat from the same pan' (FGD 5).

Another informant described a similar instance: he was believed to be turning into an animal, and people were gazing at him at night waiting for his transformation:

At the time we went to take the vaccine, [people said,] 'you can't take the vaccine and come sit right near me'. When someone takes it they will be like, 'Go! Go! Go! You're going to turn to monkey'. Monkeys. 'You will turn [in]

to [a] squirrel. You are going to change'. They said the vaccine will make us turn [in]to monkeys. So, when I'm sleeping you will see some guys with lights; they will come and be like: 'Why is this guy not changing?' (FGD 2).

This fear of transformation was internalized by some informants and used as a form of resistance. They explained that if they turned into gorillas, as rumours suggested, they would bite both researchers and community members: 'The day we get vex behind them, we will turn [in]to gorillas and be biting them. And when they ask us, we will say "it is the vaccine that is changing us"' (FGD 2).

The outcomes of looping

A common reaction to stereotyping was its internalization, as seen above in the notion that trial subjects would transform into monsters or gorillas. Other stigmatizing accounts, such as the assertion that the Ebola research unit was engaged in Ebola conspiracy also shaped how informants understood themselves. Aware of the wealth behind the research collaboration, numerous informants were expecting to receive significant compensation for their trial participation. In their eyes, money was withheld by the research teams, and notions of Ebola research as a kind of 'blood business' were common. One informant insisted: 'For me, I believe [researchers are] going to make business out of my blood. That's how I feel. That's my own feeling' (FGD 5). Another informant expressed a similar concern in an angry manner:

As for my thinking: it is business that they are going to make out of our blood. [Trial participants from marginalized areas] were planning that if the same [researchers] were going to come back, they would burn the hospital (FGD 3).

A fear of contracting sickness from the vaccine was also internalized, as one informant confided: 'As I am speaking to you now, sometimes I get sick and then I come back to myself. I don't know if it is the vaccine that is doing it' (FGD 2).

Informants explained that trial participants were avoided on the streets, and some even lost their jobs. In one interview, an informant attributed this to a fear of contagion, saying: 'I was working, but once my employer got to know I was participating in the trial test they sidelined me because they didn't want to get in contact with those who took the vaccine' (Interview 8). Another informant stated that, as a taxi driver, he had been afraid of getting Ebola from his passengers. In order to be protected, he took part in the research. But as a result, he lost his job, because his employer assumed that as a driver he would be dangerous to the community: 'I was riding the bike for my brother because I wasn't having my own, but he took the motorbike from me due to my participation in the vaccination process' (FGD 4).

Discussion

The question of stigma against trial subjects is inseparable from the specificities of the process through which trial subjects are enacted. International clinical trials, operating on the premise of commensurability and harmonization of research conduct, approach 'trial subjects' as a global category: altruistic, virtuous and sometimes vulnerable volunteers contributing to science and development. When experiments travel, such 'fragments of governmentality' are often carelessly projected onto people, communities and research settings, generating various tensions and frictions in real contexts (Sariola & Simpson, 2011). As the narratives of stigma presented here suggest, bioethical and scientific information were only one kind of socially embedded knowledge, among others involved in the making of a locally new 'trial subject' entity.

Tellingly, many interviewed trial subjects were desperate to make ends meet and trial participation offered a spontaneous economic opportunity (Alenichev & Nguyen, 2019). They were already marginalized and stigmatized in accord with various ideas held in Liberian society, in its history and presence, including notions about ex-combatants, corruption, political insecurity, devastated health-care, unsuccessful development, and *kpakpakpa*; ideas about greedy NGOs, *zogos* and bad money;

and rumours that international interventions spread Ebola and blood businesses. These accounts were all layered upon the event of the vaccine trial, suggesting yet again that medical research, as a social activity, intensifies moral experiences and exacerbates negative stereotypes (Dixon & Tameris, 2018; Saethre & Stadler, 2013; Stadler et al., 2016).

Social scientists have long asserted that conspiracy theories and supernatural stories surrounding healthcare institutions in post-colonial contexts are meaningful socially-embedded allusions to medicine, labour, and colonialism, expressed in a lay yet symbolic manner (Geissler & Pool, 2006; Grietens et al., 2014; Kingori et al., 2010; White, 2000). Following accounts of inequality, power and violence, a reading of Liberian history indicates that Ebola-related stigma and rumours, as expressions of local insecurities, might be closely tied to the fact that Liberian society was sophisticatedly stratified for nearly 200 years, wherein 'Western' and 'American' knowledge ideals, practices and features were a prerequisite for a privileged position and upward social mobility (e.g. Ciment, 2013; Dolo, 2007; Utas, 2003).

In conversation with such literature, accounts intentional infection and transformation of trial subjects into animals and monkeys can be linked to a recent history of controversial hepatitis vaccine research conducted on chimpanzees at the Liberian Institute for Biomedical Research in the 1970s-90s. In series of trials, some chimpanzees were purposefully infected with hepatitis, while others received experimental vaccine shots against it. The idea behind these interventions was to measure transmission rates and evaluate preventive abilities of the vaccines (Paye-Layleh, 2015). To approach this case as a suggestive metaphor, a locally novel event of Ebola vaccine research continued the legacy of prior US-Liberian collaborations, suggesting equivalence between human subject research and animal testing.

This multiplicity of socially-embedded knowledge and its interactions illustrates how complex real-world contexts produce looping effects that affect categories in randomized control trials that are believed to be stable and universal (Adams, 2013). Taking these ideas forward in thinking about stigma, it is possible to outline cascades of looping effects – connecting people, humans, non-humans, organizations, and interventions – all permeating the Ebola vaccine trial. This research found two distinct but connected processes that stigmatized trial subjects. The first kind emerged through the association of the Ebola vaccine with Ebola, trial subjects with Ebola carriers, and research institutions with conspiratorial organizations aimed at spreading of Ebola. In this process, trial subjects were characterized as contagious Ebola-carriers at risk of dying, who might also undergo physical changes. Some trial subjects started to feel that the vaccine contained sickness, and that they indeed might undergo physical change. The second looping pattern conflated trial subjects with marginalized populations such as poor people, substance users, NGO collaborators, and ex-combatants to name a few. The internalization of this stigma meant that, in fact, some participants started to feel that the Ebola vaccine research was indeed a part of an Ebola business, and that they were *kpakpakpa* and *zogos*. In terms of spoiling as per Goffman, the abovementioned processes correspond to more static notions of symbolic and instrumental stigma cast upon Ebola survivors, who are feared to be contagious (Bell et al., 2017; Cheung, 2015; Davtyan et al., 2014).

A number of occurring, oscillating, and re-appearing looping effects surrounding Ebola outbreak and Ebola clinical research suggest that anti-stigma interventions quickly devolved into a game of whack-a-mole: whilst community-based interventions were thoughtfully implemented to reduce stigma by counselling trial subjects and their families, providing forums for discussion in communities, and other well-intentioned efforts, the larger precarious context produced new acts of looping. Frustratingly and tragically, this complexity suggests that the ultimate solution to eradicate stigma requires the removal of its historical and intersectional layers; it requires utopian and unrealistic forms of control over the socially-embedded knowledge and feelings of people – control that cannot be achieved by ambitious attempts to design 'proper' subjectivities via social and epistemological structures within global health. Presented stories thus empirically contribute to a recent, somewhat alarming academic call to reconsider community-oriented health interventions

beyond standard emancipatory, romantic and empowering connotations (Kenworthy et al., 2018; Lavery, 2018; Reynolds & Sariola, 2018; Wilkinson et al., 2017).

In 2018, several Ebola outbreaks occurred in the Democratic Republic of the Congo and emergency Ebola vaccines were administered to healthcare workers and close contacts. Similarly to the 2014 Ebola outbreak, a widespread suspicion quickly fell on vaccine recipients, sick people, international interventions and related economic activities (Nguyen, 2019). As a response to emerging Ebola-related stigma and rumours, the World Health Organisation advised focusing on social mobilization and community engagement activities (World Health Organization [WHO], 2018). In 2019, several cases of Ebola infection were detected in Uganda, which were immediately followed by vaccination and community sensitization campaigns (WHO, 2019). In light of these events, the findings of the present study could be utilized to further explore stigma against Ebola vaccine recipients and evaluate collaborative stigma-reduction campaigns.

Conclusion

Findings from this study provide a snapshot showing that carefully designed and executed community engagement and sensitization programmes were insufficient in reducing stigma against trial subjects, hinting at a larger force that fuelled rumours and opprobrium. By approaching stigma against trial subjects as cascades of looping effects powered by socially embedded knowledge, this study suggests that contemporary research ethics should be reinforced with a more serious historical and sociological examination of the contexts in which research and community engagement practices unfold.

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References

- Adams, V. (2013). Evidence-based global public health: Subjects, profits, erasures. In J. Biehl & A. Petryna (Eds.), *When people come first: Critical studies in global health* (pp. 54–90). Princeton: Princeton University Press.
- Alenichev, A., Grietens, K. P., & Gerrets, R. (2019). Conceptions within misconceptions: Pluralisms in an Ebola vaccine trial in West Africa. *Global Public Health*, 1–9. doi:10.1080/17441692.2019.1632368
- Alenichev, A., & Nguyen, V.-K. (2019). Precarity, clinical labour and graduation from Ebola clinical research in West Africa. *Global Bioethics*, 30(1), 1.
- Bell, S. A., Munro-Kramer, M. L., Eisenberg, M. C., Williams, G., Amarah, P., & Lori, J. R. (2017). “Ebola kills generations”: Qualitative discussions with Liberian healthcare providers. *Midwifery*, 45, 44–49.
- Benton, A. (2017). Whose security? Militarization and securitization during West Africa’s Ebola outbreak. In M. Hofman & S. Au (Eds.), *The politics of fear: Médecins sans Frontières and the West African Ebola epidemic* (pp. 25–50). New York: Oxford University Press.
- Bos, A. E. R., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology*, 35(1), 1–9.
- Campbell, N. D., & Stark, L. (2015). Making up ‘vulnerable’ people: Human subjects and the subjective experience of medical experiment. *Social History of Medicine*, 28(4), 825–848.

- Chandler, C., Fairhead, J., Kelly, A., Leach, M., Martineau, F., Mokuwa, E., ... Wilkinson, A. (2015). Ebola: Limitations of correcting misinformation. *The Lancet*, 385(9975), 1275–1277.
- Cheung, E. Y. L. (2015). An outbreak of fear, rumours and stigma: Psychosocial support for the Ebola virus disease outbreak in West Africa. *Intervention*, 13(1), 45–84.
- Ciment, J. (2013). *Another America: The story of Liberia and the former slaves who ruled it*. New York: Hill and Wang.
- Davtyan, M., Brown, B., & Folyan, M. O. (2014). Addressing Ebola-related stigma: Lessons learned from HIV/AIDS. *Global Health Action*, 7, 26058.
- Dixon, J., & Tameris, M. (2018). Clean blood, religion, and moral triage in tuberculosis vaccine trials. *Medical Anthropology*, 37(8), 708–721.
- Doe-Anderson, J., Baseler, B., Driscoll, P., Johnson, M., Lysander, J., McNay, L., ... Zuckerman, J. (2016). Beating the odds: Successful establishment of a phase II/III clinical research trial in resource-poor Liberia during the largest-ever Ebola outbreak. *Contemporary Clinical Trials Communications*, 4, 68–73.
- Dolo, E. (2007). *Ethnic tensions in Liberia's national identity crisis: Problems and possibilities*. Cherry Hill: Africana Homestead Legacy Publishers.
- Epstein, H. (2015, December 18). Ebola in Liberia: An epidemic of rumors. *The New York review of books*, 1–16. Retrieved from <https://www.nybooks.com/articles/2014/12/18/ebola-liberia-epidemic-rumors/>
- Geissler, P. W., & Pool, R. (2006). Editorial: Popular concerns about medical research projects in sub-Saharan Africa—A critical voice in debates about medical research ethics. *Tropical Medicine & International Health: TM & IH*, 11(7), 975–982.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs: Prentice-Hall.
- Grietens, K. P., Ribera, J. M., Erhart, A., Hoibak, S., Ravinetto, R. M., Gryseels, C., ... D'Alessandro, U. (2014). Perspective piece: Doctors and vampires in Sub-Saharan Africa: Ethical challenges in clinical trial research. *American Journal of Tropical Medicine and Hygiene*, 91(2), 213–215.
- Hacking, I. (1991). The making and molding of child abuse. *Critical Inquiry*, 17(2), 253–288.
- Hacking, I. (2007). Kinds of people: Moving targets. In *Proceedings of the British Academy, Volume 151, 2006 Lectures* (pp. 285–317). British Academy. doi:10.5871/bacad/9780197264249.003.0010
- Hatzenbuehler, M. L. (2016). Structural stigma: Research evidence and implications for psychological science. *The American Psychologist*, 71(8), 742–751.
- Hoffman, D. (2016). A crouching village: Ebola and the empty gestures of quarantine in Monrovia. *City & Society*, 28, 1548–1744.
- Holt, M. (2013). Enacting and imagining gay men: The looping effects of behavioural HIV surveillance in Australia. *Critical Public Health*, 23(4), 404–417.
- Jones, J. (2014). Ebola, emerging: The limitations of culturalist discourses in epidemiology. *The Journal of Global Health*. Retrieved from <http://www.ghjournal.org/ebola-emerging-the-limitations-of-culturalist-discourses-in-epidemiology/>
- Kennedy, S. B., Neaton, J. D., Lane, H. C., Kieh, M. W., Massaquoi, M. B., Touchette, N. A., ... Nyenswah, T. G. (2016). Implementation of an Ebola virus disease vaccine clinical trial during the Ebola epidemic in Liberia: Design, procedures, and challenges. *Clinical Trials*, 13(1), 49–56.
- Kenworthy, N., Thomas, L. M., & Crane, J. (2018). Introduction: Critical perspectives on US global health partnerships in Africa and beyond. *Medicine Anthropology Theory | An Open-Access Journal in the Anthropology of Health, Illness, and Medicine*, 5(2). doi:10.17157/mat.5.2.613
- Kingori, P., Muchimba, M., Sikateyo, B., Amadi, B., & Kelly, P. (2010). "Rumours" and clinical trials: A retrospective examination of a paediatric malnutrition study in Zambia, southern Africa. *BMC Public Health*, 10(1), 556.
- Kleinman, A., & Hall-Clifford, R. (2009). Stigma: A social, cultural and moral process. *Journal of Epidemiology & Community Health*, 63(6), 418–419.
- Lavery, J. V. (2018). Building an evidence base for stakeholder engagement. *Science*, 361(6402), 554 LP–556.
- Lock, M., & Nguyen, V.-K. (2010). *Anthropology of biomedicine*. Singapore: Wiley-Blackwell.
- Matthews, S., Dwyer, R., & Snoek, A. (2017). Stigma and self-stigma in addiction. *Journal of Bioethical Inquiry*, 14(2), 275–286.
- Moyer, E., & Nguyen, V. (2015). Everyday afflictions in global context. *Medicine Anthropology Theory*, 2(2), 1–3. Retrieved from https://pure.uva.nl/ws/files/25669949/en_moyer_mat_v2_2.pdf
- Nguyen, V. K. (2019, April 4). An epidemic of suspicion — Ebola and violence in the DRC. *New England Journal of Medicine*, 380, 1298–1299. Massachusetts Medical Society.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine*, 57, 13–24.
- Paye-Layleh, J. (2015). Stranded on Liberia's lab chimp islands. Retrieved from <https://www.bbc.com/news/world-africa-34154070>
- Perry, J., & Sayndee, T. D. (2016). *Social mobilization and the Ebola virus disease in Liberia*. Lanham: Hamilton Books.
- Reynolds, L., & Sariola, S. (2018). The ethics and politics of community engagement in global health research. *Critical Public Health*, 28(3), 257–268.
- Saethre, E., & Stadler, J. (2013). Malicious whites, Greedy women, and virtuous volunteers. *Medical Anthropology Quarterly*, 27(1), 103–120.

- Sariola, S., & Simpson, B. (2011). Theorising the “human subject” in biomedical research: International clinical trials and bioethics discourses in contemporary Sri Lanka. *Social Science and Medicine*, 73(4), 515–521.
- Stadler, J., Scorgie, F., van der Straten, A., & Saethre, E. (2016). Adherence and the lie in a HIV prevention clinical trial. *Medical Anthropology: Cross Cultural Studies in Health and Illness*, 35(6), 503–516.
- Tete, B. (2016, October 21). The war against ‘Zogos’ is commendable, but must be holistic and systematic. *Liberian Observer*.
- Utas, M. (2003). *Sweet battlefields: Youth and the Liberian civil war*. Uppsala: Uppsala University.
- White, L. (2000). *Speaking with vampires: Rumor and history in colonial Africa*. Oakland: University of California Press. doi:10.2307/220669
- Wilkinson, A., & Leach, M. (2015). Briefing: Ebola—Myths, realities, and structural violence. *African Affairs*, 114(454), 136–148.
- Wilkinson, A., Parker, M., Martineau, F., & Leach, M. (2017). Engaging ‘communities’: Anthropological insights from the west African ebola epidemic. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 372(1721), 20160305.
- World Health Organization. (2018). Ebola virus disease – democratic Republic of the Congo. Retrieved from <https://www.who.int/csr/don/06-july-2018-ebola-drc/en/>
- World Health Organization. (2019). Ebola virus disease – Republic of Uganda. WHO. Retrieved from <https://www.who.int/csr/don/13-june-2019-ebola-uganda/en/>