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Conceptions within misconceptions: Pluralisms in an Ebola vaccine trial in West Africa

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ABSTRACT

Ensuring that biomedical information about research procedures is adequately understood by participants and their communities is key for conducting ethical research. This article explores participants' understanding of trial procedures for an experimental vaccine against Ebola virus disease (EVD) in a West African context. We found that some trial participants believed there was a chance of contracting Ebola and other sicknesses from the vaccine, and others believed both the vaccine and the placebo control would be able to prevent other illnesses than EVD. While these beliefs might be understood as misconceptions about the vaccine trial, this paper shows that such a conclusion is problematic because it excludes local explanatory health models and logics of causality. The paper invites bioethicists to work with anthropologists to take seriously different models of health knowledge in global health research. Investigating and addressing such differences could be the key to understanding human subjects' motives for participation, and to creating space for studies of empirical ethics.

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Introduction

How best to provide information to research participants remains an important topic in international research ethics. In accordance with the tenets of clinical research, people asked to participate in research should be informed by researchers about the focus of the research project, why it is being conducted and by whom, the risks and benefits of participating, the placebo concept, and other relevant topics. Drawing on such information, participants are expected to consider their own risks and benefits and take an informed decision on whether to participate or not. In the era of increasingly globalised and harmonised clinical research, consent procedures generally assume that biomedical knowledge is the standard against which understanding is ascertained; gaining consent implies that the participant understands the risks and benefits in similar terms to the researcher (Belkin, 2006).

While the format of obtaining informed consent is designed to treat people equally, people's life-worlds and knowledge systems are often vastly dissimilar. Anthropologists have long shown the situatedness and plurality of knowledge and practices embedded in diverse social, political and economic contexts. Extensive studies have explored logics and rationales involving diverse health-related knowledge and practices beyond biomedicine (Olsen & Sargent, 2017). Moreover, health-related

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knowledge can take the form of more or less internally coherent ‘systems’ (Last, 1981), but it can also take hybrid forms – for instance when communities appropriate and modify biomedical information in ways that recall local ways of understanding and treating illness (Hausmann Muela, Muela Ribera, Mushi, & Tanner, 2002; Pigg, 2001).

In applied contexts of clinical research and public health interventions, such reinterpretation of health-related knowledge, especially when this results in divergences from biomedical premises, is often viewed as problematic (Yoder, 1997). Such deviations are regularly attributed to misconceptions, confusions, hopes, cultural superstitions, and other misunderstandings. Reflecting this logic, organisations routinely distinguish between biomedical and ‘other’ knowledge. The World Health Organisation, for instance, maintains a strict separation between biomedical and non-biomedical knowledge, lists ‘six common misconceptions about immunization’, and calls people to ‘embrace the facts about vaccines, not the myths’ (World Health Organization, 2013, 2017). In a similar manner, the European Centre for Disease Prevention and Control highlights a need to correct myths about the measles vaccination (European Centre for Disease Prevention and Control, 2019).

Clinical research activities, which usually involve some communication about health- or disease-related issues, can also elicit misconceptions. Bioethicists have raised the concern of so-called therapeutic misconception, a term that broadly refers to ‘false beliefs, unrealistic expectation, or poor understanding of the purpose of clinical trials’ among trial subjects (Malan & Moodley, 2016). Examples are, for instance, approaching clinical research as a source of healthcare, and perceiving clinical researchers to be clinical providers in trials. Bioethicists also acknowledge ‘preventive misconception’, which is defined as ‘a misunderstanding in which research participants make an over-estimation in probability or level of personal protection that is afforded by being enrolled in a trial of a preventive intervention’ (Simon, Wu, Lavori, & Sugarman, 2007). Preventive and therapeutic misconceptions have been detected and problematised in several clinical trials conducted in Sub-Saharan Africa (Lema, 2009; Sugarman et al., 2019; Woodsong et al., 2012). In light of the 2014 Ebola outbreak in West Africa, therapeutic and preventive misconceptions have been flagged as potential problems for Ebola vaccine research development in low literacy research communities (Calain, 2018; Folayan, Yakubu, Haire, & Peterson, 2016; Klitzman, 2015). The bioethical literature generally suggests that various misconceptions about participation could be minimised by educating people, adjusting their behaviours, and optimising a process of provision of biomedical information in a lay and reflexive manner (Asgary, Grigoryan, Naderi, & Allan, 2012).

Currently, relatively little is known concerning the uptake of knowledge about ‘Ebola vaccine research’ among trial subjects in West Africa. In this paper, we approach health-related knowledge as a dynamic and varying process in an Ebola vaccine trial in Liberia that was launched in 2014, and successfully completed in 2016. Guided by the best bioethical practices, Ebola vaccine trial implementers established rigorous communication with participants and their communities. Various Ebola-related myths, rumours and misconceptions were addressed in a comprehensive and rigorous manner based on epidemiological principles. For instance, trial implementers trained so-called trial educators who organised workshops for potential trial subjects. In these workshops, Ebola vaccine research and related procedures were explained in lay language with attention to the context. Workshops were followed by individual consent procedures. Trial implementers also established a hotline for trial subjects in order to address any questions, concerns or complaints they had about participation. Several community mobilisation and sensitisation teams actively worked on the ground within communities. Information about the trial was presented, and subsequently explained in a series of discussions with formal community leaders, traditional artists and healers. Moreover, trial implementer teams trained so-called trackers – people from the community who acted as a link between researchers and participants, and individually addressed trial subjects’ questions, concerns and complaints over a course of frequent counselling and follow-up visits.

In this article, we explore trial subjects’ understandings – conceptions and misconceptions – regarding the meaning of an ‘Ebola vaccine’. By drawing on debates in medical anthropology and deploying the theoretical framework of bioethics, we invite the reader to think about health-related

knowledge in clinical trials as a process situated in and influenced by larger pluralist contexts and day-to-day realities.

This research was part of larger qualitative research conducted in 2016 aimed at a retrospective exploration of trial subjects' participatory experiences, six months after the Ebola vaccine trial was officially completed. The core study has been published elsewhere (Alenichev & Nguyen, 2019). Eleven semi-structured interviews and five group discussions with vaccine trial participants were carried out. In total, 25 informants were interviewed. It was conducted independently of trial organisers, and authors do not hold any affiliations with related institutions. The study was formally approved by the Ethics Committee of the University of Amsterdam, and the Ethics Board of the University of Liberia. In the preparatory stage, the project was informally approved by local community leaders and researchers conducting Ebola vaccine research. Written informed consent, in a format approved by the ethics boards, was obtained from each participant. Details about respondents and the community have been modified to ensure confidentiality.

Findings

An illusion of commensurability of biomedical knowledge

According to informants, a typical workshop for participants involved a discussion of the following topics: (1) Ebola vaccine research study, (2) vaccines, (3) voluntary participation in the study, (4) after-consent procedures, (5) blood testing, (6) information about the vaccines, (7) placebo, (8) randomisation, (9) administration through injection, and (10) follow-up procedures. Informed consent forms for participation in the vaccine trial contained detailed descriptions of both the vaccines and Ebola, which were framed in accessible and lay language:

Vaccines are used to prevent people from getting certain diseases. Many people get vaccines to prevent flu, measles, polio and tetanus ... A vaccine help your body to fight off a particular germ if you come in contact with it ... now there are no vaccines to stop people from getting sick with Ebola ...

Despite such well-intended efforts of vaccine research teams to educate participants and their communities, we found out that information provided about the Ebola vaccine was not always understood as intended. Nearly all informants expressed heterogeneous perspectives about the meanings of the 'Ebola vaccine research' they were once part of, as the following response exemplifies.

They [researchers] said [the vaccine] would protect us against Ebola, different-different signs. (FGD 5)

While some informants described the vaccine as solely targeting Ebola, many said, in both interviews and group discussions, that they thought the vaccine was good for health and could prevent sickness more broadly. Informants also described how researchers explained an Ebola vaccine as a system to prevent diseases in general, indicating that the meaning of the Ebola vaccine was appropriated and modified:

[In the workshop, researchers] explained to me about the vaccine. Like how is it used for the body, in the system. Like to prevent it from [getting] other disease and sicknesses. [The most important information] was that the vaccine was very good for prevention ... against any other diseases, like malaria and other diseases. (Interview 2)

Moreover, differing from the biomedical view of the vaccine as a disease-specific preventive intervention, some informants understood an Ebola vaccine as possessing protective qualities extending beyond EVD. In the following excerpt, an informant who had received the placebo described the vaccine as being able to prevent people from getting sick, and 'flush everything out':

[Researchers] explained about a lot of small sicknesses that the vaccine will prevent you from getting sick, that any kind of sickness that will come to Liberia. You will be prevented from it including malaria, chronic cold –

the vaccine can flush everything out. Since I took the vaccine I haven't gotten malaria or any other sickness, I don't feel sick and for me to get sick is very hard. (Interview 3)

This indicates that carefully designed sessions to educate participants and gain their informed consent, even when backed up by robust information-provision strategies, do not necessarily bring researchers and participants to the same understanding of fundamental trial concepts and procedures. As these findings suggest, there is a need to question the presumption that biomedical knowledge will be taken up in unchanged form, even when health communication activities are reinforced with sophisticated and well-executed community participation approaches.

Alienating people through 'misconceptions'

What can be said about those quotes? Findings from this study clearly indicate a case of informants' therapeutic and preventive misconceptions. As another example, some informants explained that experimental vaccination offered protection against Ebola and other sicknesses that come with Ebola:

It's a prevention vaccine. It can prevent other sickness in you, because Ebola comes with a lot of sickness, such as malaria, running stomach, fever. (FGD 4)

Informants clearly attributed pluripotent efficacy to the vaccine:

The vaccine will protect me from Ebola and any other disease but mostly from Ebola ... I took the vaccine because of my health. (Interview 5)

Other informants listed the following conditions expected to be prevented by the experimental Ebola vaccination: 'the sickness', 'Ebola', 'a lot of small sickness', 'minor sicknesses', 'signs of Ebola', 'any disease', 'malaria', 'cold', 'signs of Ebola', 'chronic cold', 'every disease', 'every sickness in your body'.

Informants' understanding of the placebo also varied: some informants understood it as a compound without any therapeutic effect; others expected it to act as a vaccine to prevent sickness. Even when informants did understand the meaning of placebo, preventive abilities were attached to it, as the following excerpt exemplifies:

Interviewer: Do you feel protected against Ebola?
 Interviewee: As for me, I took the salt water so I'll say I feel protected.
 Interviewer: You said you took the salt water, the placebo, and you're saying you feel protected against Ebola.
 Interviewee: Yes, because since then I've never been sick (FGD 5).

As one of the informants attested, the notion of protection appeared right after an injection, echoing the abovementioned example of an injection as a powerful intervention:

I just felt I have taken the injection, I felt protected when I just took the vaccine. (FGD 5)

Informants also had fears that the Ebola vaccine spreads sickness as people did not fully understand the idea of adverse events of experimental products:

Many people were saying that many people were going to die from the vaccination. We were at risk ... Ah, desperate, but as God could have it, we are still living and we will not die just now ... But some of our friends die[d] because the vaccine brought out their problems – hidden sickness – like one of my friends, he had a kidney problem. (FGD 2)

The discourse of misconceptions, myths and misestimations raises an important epistemological concern. From participants' own perspectives, their interpretations of the Ebola vaccine's efficacy are not misconceptions, but they are portrayed as such by people who subscribe to the biomedical standard. When declared a misconception, a myth, or a misestimation on behalf of a public health and bioethical authority, the knowledge of the 'other' is placed beyond the borders of serious recognition, and is flagged as inferior loci as opposed to the 'conception' and a system sustaining it. For instance, during the 2014 Ebola outbreak the public health discourse of Africans' misconceptions

about Ebola reproduced accounts of African ignorance, backwardness and deficiency of reason (Jones, 2014). That kind of repudiation resonates with long-standing concerns in post-colonial studies and anthropology on how colonial powers mobilised knowledge ideals and biomedicine to justify and legitimise the subjugation of people and their knowledge systems in the name of modernity and progress (Comaroff, 1993; Prince & Marsland, 2013).

The term 'misconception' always invokes a visible or invisible point of reference, is that standard against which certain conceptions are viewed as 'mis'. What is troublesome is not mentioning this standard, but also not clarifying, not concretising or failing to acknowledge that imposing or privileging it over other forms of knowledge might not be appreciated or supported by the intended recipients of such knowledge. More tangibly, in order to avoid bioethical and biomedical dismissiveness of others, it is essential to accept the fact that what are routinely identified as therapeutic and other 'misconceptions' are in fact conceptions with their own logic and rationale (Graboyes, 2015; Stewart & Sewankambo, 2010). Injections and needles, for instance, are known to have unintended meanings in various contexts (Reeler, 2000; Whyte & van der Geest, 1994). In West Africa, ideas about strength, fluid and substance do not conform to biomedical notions; the act of penetrating skin and injecting during immunisation is commonly viewed as having various powerful impacts on bodies, including strengthening health (Leach & Fairhead, 2008). Thus, informants' expectations of further therapeutic and preventive benefits from injections, whether of the vaccine or placebo, beyond its specific target of EVD, could be local variants of how injections are understood in accordance with local knowledge formations, logics of causality and related social practices.

Anthropologists have also established that in many African contexts, explanatory models for sickness are based on categorising and treating symptoms rather than aetiological agents as the authority of the biomedical worldview dictates (Olsen & Sargent, 2017). Malaria, for instance, carries variable meanings in many contexts, including Liberia, because of a variety of symptomatic manifestations and related interpretations (Gryseels et al., 2015; Jackson, 1985; Muela, Ribera, & Tanner, 1998). A similar situation was documented during the Ebola outbreak in Liberia: Several qualitative studies hinted at an ambiguous conception of 'Ebola' as an amalgamation of symptoms that was classified and treated in accordance with symptomatic patterns of vomiting, diarrhoea, fever, fatigue and pain (Abramowitz et al., 2015; McLean et al., 2018; Omidian, Tehoungue, & Monger, 2014). Biomedical knowledge about the Ebola virus was incorporated into local beliefs about health and the logics of causation. For instance, Ebola was also perceived to be especially fatal during the rainy season, when incidences of cholera and malaria in Liberia increase (Omidian et al., 2014), nursing local perceptions that these three diseases were connected.

During the Ebola outbreak, sick people with a symptomatic pattern of fever, headache, nausea, vomiting and diarrhoea were reported to officials as Ebola patients, further blurring lines between Ebola and other sicknesses (Benton, 2018).

Moreover, both formal healthcare and education structures, which in theory support biomedical health communication, were heavily damaged during the Liberian civil war crisis, and directly contributed to the impact of Ebola in West Africa (Leach, 2015; Wilkinson & Leach, 2015; Wilkinson & Fairhead, 2017). The lack of effective health communication infrastructure was why many of the informants explained that the Ebola vaccine, wherein Ebola was understood as a 'sickness' that affected West Africa, offered broad protection against symptoms of Ebola regardless of their aetiological causality.

Thus, categorising non-biomedical worldviews as misconceptions, misestimations and myths is not only unhelpful but also potentially offensive, as it would be equal to blaming the lack of shared understanding on local peoples' apprehensions, lived experiences, practices, and explanatory models. Such examples, which recall discussions of 'violence of concepts' and the 'violence of philosophical discussion', show yet again that bioethics should take into consideration the questions of power and relational responsibility while privileging any position or understanding over others (Gibson, 2015).

Consenting to what? Trust, disappointment and invincibility

Among informants, the vaccine's preventive abilities to protect beyond aetiologically defined EVD were considered important and, along with monetary incentives, the main reasons reported for participation. The following excerpt shows how an informant approached the Ebola vaccine as an intervention that would help avoid the contracting of sickness:

The vaccine is for prevention from the sickness that was coming, like malaria, cold, Ebola ... I wanted to live. I didn't want to contract sickness, that's why I took the vaccine. (Interview 6)

Another informant explained that prevention of the sickness that was ravaging the country was a common reason for trial participation:

Many people took the vaccine for prevention, because the sickness that was within the country was killing plenty [of] people, so some of us started going to take the vaccine, and started to encourage our friends, saying that 'the vaccine isn't bad, it's for prevention of sickness within the country'. (FGD 4)

Understanding the act of injecting as powerful and generating some protection in its own right, coupled with the understanding that a vaccine against Ebola can also offer protection against various other diseases/illnesses, raises a fundamental question for research ethics: How did people interpret the consent process – specifically what did they think they consented to? Ebola trial participants who expect to be protected against sickness in general are likely to be disappointed when they experience illness in the future. In 2010 alone the WHO reported 1,265,268 cases of malaria in Liberia, in a population of less than 5 million; hospital records suggest that at least 33% of all inpatient deaths in Liberia in 2010 were due to malaria (World Health Organization, 2014). While the data collected were not intended to provide insight into changes in risk behaviour, it is likely that expectations of prevention may produce a false sense of protection, which could affect individuals' behaviour in terms of the day-to-day safety measures they take. When sick – despite their perceived newly gained immunity against the 'the sickness', 'Ebola', 'a lot of small sickness', 'minor sicknesses', 'signs of Ebola', 'any disease', 'malaria', 'cold', 'signs of Ebola', 'chronic cold', 'every sickness in your body', – participants might develop mistrust, anger, and disappointment about the vaccine, its researchers, and public health institutions involved in the trial.

Thus, inability to address local models of health-related knowledge and logics of causality by simplifying them as misconceptions could hamper trust building efforts and contribute to overconfidence and subsequent risky behaviours.

A step forward: A call to consider knowledge as a dynamic process

In the aftermath of this and other Ebola outbreaks in West Africa, testing theories and developing methods to address emergent problems is one of the priorities for future outbreak responses (Graham et al., 2018). This work shows that qualitative research is a valid and important tool to detect pluralist perspectives in contexts where the centrality of biomedicine is taken for granted, and that the presence of multiple understandings can act both as a barrier and a facilitator to interventions. This article adds to the discussions regarding the implications of reconceptualisation of non-biomedical understandings of diseases and different knowledge-based constructions for ethical research conduct (Grietens et al., 2014; Kingori, Muchimba, Sikateyo, Amadi, & Kelly, 2010).

In 2018, several Ebola outbreaks happened in the Democratic Republic of Congo (Barry et al., 2018). Just like in many places in Africa, the Democratic Republic of Congo is a multicultural country where heterogeneous models of health knowledge, healthcare systems and worldviews coexist, interact and merge. Surrounded with mistrust, rumours and violence, emergency Ebola vaccinations were initiated with the goal of establishing collaborative interventions within exposed populations (Nguyen, 2019). The present study thus presents specific implications for clinicians, trial conductors, bioethicists, and social scientists working in the DR Congo and other contexts. This article presents two challenges: how to take epistemological pluralism and ambiguities of

concepts seriously, and how to go beyond the discourse of ‘myths’ and ‘misconceptions’. There is a vital need to explore epistemological pluralism in the context of Ebola research in order to grasp what exactly is understood regarding terms and concepts such as ‘Ebola’ and ‘vaccine’. We invite anthropologists and bioethicists to jointly theorise knowledge systems in global health research and encourage future studies to investigate the meanings attributed to the ‘Ebola vaccine’ in West Africa and elsewhere.

Study limitations

What this article presents is a snapshot relating to what informants say they think about Ebola vaccine research. Respondents’ interpretations and concerns may bear little relation to their practices. It is indeed unclear what informants meant by ‘Ebola’, ‘Ebola vaccine’, ‘placebo’, ‘clinical research’, ‘malaria’, ‘adverse events’ and ‘symptoms’ – and the robust way for theorising these is to conduct long-term ethnography, which this work did not provide. However, what is evident from the data is that knowledge about the Ebola vaccine was generated and deployed within epistemological infrastructures that were not managed by optimal bioethical models of practicing ethics that a priori assume commensurability of that knowledge through community participation activities. Trial participants understood the experimental Ebola vaccine through local interpretations of biomedical information following local illness perceptions and ideas about causality. These interpretations are beyond biomedical realities and in parallel to complex community participation activities and careful informed consent procedures, which, in theory, were supposed to minimise ‘misconceptions’.

One of the key issues with any kind of empirical bioethics is the ‘is-ought problem’ (Dunn, Sheehan, Hope, & Parker, 2012). As such, this article does not aim to draw prescriptive claims based on limited empirical accounts, nor does it try to produce heuristic answers to long-standing discussions in bioethics and medical anthropology. Moreover, our aim is not to superficially state that ‘everything is relative’. Instead, this article advocates for the case of pluralism: People have different understandings which operate within their own logic and rationale, and their views interact in various and often unexpected ways. Our paper highlights that research teams cannot be blamed for under-informing participants because health knowledge exists prior to and beyond any project’s influence.

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