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Reaching out to Ebola victims: Coercion, persuasion or an appeal for self-sacrifice?

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ABSTRACT

The 2014–2015 Ebola crisis in West Africa has highlighted the practical limits of upholding human rights and common ethical principles when applying emergency public-health measures. The role of medical teams in the implementation of quarantine and isolation has been equivocal, particularly when such measures are opposed by communities who are coerced by the temporary suspension of civil liberties. In their encounters with Ebola victims, outreach teams face moral dilemmas, where the boundaries are unclear between coercion, persuasion and appeals for self-sacrifice. For those teams, we propose a set of practical recommendations aimed at respecting the autonomy of epidemic victims and easing tensions within communities. We recognize that some of these recommendations are progressively achievable, depending on the specific stage or setting of an outbreak. Yet with the increasing availability of experimental treatments and research interventions, weighing patients' autonomy against the common good will become an even more pressing ethical obligation.

1. Introduction

It is now commonplace to say that the 2014–2015 epidemic of Ebola virus disease (EVD) in West Africa has been 'unprecedented', owing to its magnitude, societal impact, regional dimension and international spread. The disarray of local health systems, the mobility of populations, the shortcomings of global health institutions and the absence of an effective regional mechanism for outbreak response are held as prominent reasons for the delayed containment of the epidemic in Guinea, Sierra Leone and Liberia. In such exceptional circumstances, conventional public-health activities to control Ebola outbreaks have magnified unresolved ethical issues and exposed the complexity of tensions between individual autonomy and the common good. Front-line responders striving to implement urgent public-health measures have been working in an unusually difficult context, marked by the temporary suspension of civil liberties, controversial quarantine measures, weak human-rights protection, questionable public-health strategies and blurred responsibilities. These conditions have made encounters between relief workers and Ebola victims ethically problematic and prone to generating moral distress (Ulrich, 2014). This essay will examine how patients' autonomy has been sacrificed to the public-health necessities imposed by the 2014–2015 Ebola epidemic. With a focus on forcible isolation, we will develop three problematic dimensions of epidemic-control activities. Firstly, we will argue that socio-political accounts of the frequent resistance of populations to public-health actions have left aside ethical perspectives in general and the question of autonomy in particular. Secondly, we will examine how coercive measures taken during the West African epidemic have failed to meet human rights or ethical standards and how non-governmental actors have reacted to these measures. Thirdly, we will compare the respective strengths of practical and moral reasons that might justify facility isolation with those generally put forward against quarantine. Finally, we will offer recommendations to clarify and ease the position of non-state actors towards coercive measures used in times of major epidemics.

2. Filovirus outbreaks: explanatory models of resistance and violence

The public-health response to outbreaks of the Ebola and Marburg viruses (members of the *Filoviridae* family, henceforth called 'filovirus') has essentially remained the same since the first verified occurrence of EVD in 1976. For biomedical experts, a number of public-health measures are essential and generally seen as uncontroversial: centralized case isolation (i.e. the management of

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confirmed cases in designated health-care facilities with maximal biosafety procedures), case finding (through active surveillance, follow-up of rumors and contact tracing), safe burial rites, social mobilization, health promotion and the reinforcement of standard precautions. Other measures remain disputed, for example individual or mass quarantine, border closures or social distancing. Regardless of the scientific authority of public-health prescriptions, collective reactions of fear, disbelief, rumor or hostility have historically been encountered by many relief and scientific teams in their approaches to communities affected by filovirus outbreaks. This was already the case in 1995 when Ebola spread to Kikwit (currently Democratic Republic of the Congo) (Garrett, 2001). In 2001–2002 during an outbreak of EVD in a remote location straddling the border between Gabon and Congo, the reluctance of villagers to collaborate with outbreak-investigation teams created security conditions that forced international members to evacuate the area twice (WHO, 2003). In 2003, health workers received death threats and suffered acts of violence when Ebola broke out again in the same rural setting of Congo (Formenty et al., 2003). Prior to the arrival of researchers, four teachers accused of spreading the disease were assassinated in the town of Kélé. Rural areas are not the only cases. Urban settings have also been the theater of hostility and violence, notably during filovirus outbreaks in Gulu (Uganda) in 2000–2001 (Hewlett and Hewlett, 2005) and in Uige (Angola) in 2005 (Roddy et al., 2007).

Unsurprisingly West Africa has experienced the same sort of reactions, whereby national and international teams tasked with public-health activities have been facing recurrent and widespread hostility from many affected communities. There are frequent reports of patients in hiding or refusing to present to treatment facilities. In Sierra Leone, during the most recent period of enforced lockdown, systematic home searches found that about one third of all patients had previously not been identified by contact tracing (Sahid, 2015). In Guinea, the frequency of incidents has been monitored by Guinean authorities since November, 2014 (Reliefweb, 2015) by recording the weekly number of sub-prefectures reporting *réticences*. *Réticences* (as opposed to the more politically charged "resistance") is a neutral qualifier that encompasses all instances of opposition to either contact tracing, transfer to isolation, safe burials or other public-health interventions (ACAPS, 2015a). Examples given in national weekly reports include the refusal to be put in isolation, verbal violence, vandalism, death threats, the stoning of cars or physical aggression towards outreach teams. In Guinea, the geographical spread of *réticences* culminated in January, 2015, with 32 of the 341 sub-prefectures or urban communes reporting incidents. As of April, 2015 a few areas close to the capital city of Conakry remained hostile to outreach teams. Local measures taken by the Guinean authorities have generally focused on mass communication and interventions by peers, religious leaders or traditional authorities. In January 2015, the President of Guinea authorized the use of force against those who oppose to Ebola control measures (Diallo, 2015). The open epidemiological category of *réticences* is misleading, as it conflates two morally distinct actions, i.e. the legitimate reluctance of individuals to comply with extreme public-health measures and genuine acts of violence. On top of minor daily incidents, a number of extremely violent events have affected and delayed the work of relief organizations. On 4 April, 2014 in Guinea, less than three weeks after the confirmation of the outbreak, mobs in the town of Macenta threatened Médecins sans Frontières (MSF) teams, forcing the suspension of all Ebola-control activities for one week. In September 2014 in Womey (Forest region, Guinea) eight members of a high-ranking delegation were murdered, including three health officials. The same month, Red Cross teams collecting dead bodies were attacked in the mining town of Forecariah. In Sierra Leone, similar incidents occurred in Koidu in October, 2014, leaving two dead and residents under curfew (Ruble, 2014). The incident followed an attempt by health officials, to take an elderly woman to an Ebola treatment center against the will of family members. In Liberia, the township of West Point in Monrovia was the theater of major incidents in August 2014 after mobs looted an Ebola clinic. Soon after, clashes with security forces followed quarantine and curfew orders, leaving many wounded and one dead from gunshot wounds.

The political dimension of civil unrest that accompanies major Ebola outbreaks is omnipresent and complex. In West Africa, opposition to public health authorities has been interpreted as an expression of the social divisions left successively by the colonization, civil wars, and post-conflict development policies. In Guinea for example, the frequent resistance to Ebola-response activities reflects both historical and contemporary factors, themselves influenced by national and international circumstances. In the Forest region, where the Ebola epidemic started, long-lasting secular conflicts still divide communities and generate mistrust against national authorities (Anoko, 2015). In addition, memories of coercive public health measures during the colonial era, mixed with resentment about past international clinical trials entertain rumors of an intentional origin of the disease (ACAPS, 2015a). Putting the epidemic in a broader international context, Wilkinson and Leach (2015) see local resistances to epidemic response as a consequence of the structural violence and inequalities that prevail in post-colonial Africa, exacerbated by the inevitable presence of foreign or international agencies working in support of national authorities. Examining international biomedical perspectives, Leach and Hewlett (2010) have shown how a 'global outbreak' narrative pervades health policies and their interpretation of epidemic events. This narrative privileges scientific authority over local knowledge and calls for external remediation, ignoring how popular knowledge can integrate with biomedical science. In a narrow interpretation, the global outbreak narrative shifts the blame to victims, variably accused of medical superstitions, unsafe burials, consumption of infectious wild game, or the shunning of Ebola treatment centers.

Aside from political contexts, medical anthropology provides another explanatory framework. With their pioneering field work in Uganda (Hewlett and Hewlett, 2008), Congo (Formenty et al., 2003; Hewlett et al., 2005) and Gabon (Hewlett and Hewlett, 2008), anthropologists have documented how hostile reactions to public-health measures reflect a divide between biomedical representations of EVD and other cultural models prevailing in African societies. For example, traditional and biomedical communities would typically diverge in their interpretations of disease, contagion and healing, in the way they conduct protective rituals, in their handling of the deceased during burial rites, or in their understanding of risk groups and sources of the disease. Anthropological approaches are essential to guide the response to filovirus epidemics through community engagement (Epelboin, 2015; Marais et al., 2015), mediation (Anoko, 2015) and flexibility in the application of biomedical models (Chandler et al., 2015). At the same time, anthropological perspectives are incomplete and run the risk of patronizing interpretations if cultural aspects of resistances are taken at face value. Cultural explanations alone discount the capacity for autonomous decision-making, expected from anyone exposed to the consequences of contagion and regardless of national or cultural affiliations. In other words, reactions of disbelief or opposition to public-health measures are rational and universal and would likely be felt by many of us facing the prospect of quarantine, isolation, social ostracism, suffering and possible death. Practically, communities are keen to incorporate traditional and biomedical models in a form of medical pluralism compatible with