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Ebola and the narrative of mistrust

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> They who have put out the people's eyes, reproach them of their blindness.
> –John Milton, *Apology for Smectymnuus* (1642)

Summary box

- Transmission of Ebola virus in West Africa and the Democratic Republic ofthe Congo has been traced to local people's belief in misinformation and low trust in institutions.
- But such analyses—and others—of Ebola transmission employ bourgeois empiricist methodologies and draw from a mental map whose contours are shaped by *coloniality*.
- By tracing human rights failings to the impoverished discursive infrastructure of objectivist epidemiology, we can transform global health by transforming its representations.

INTRODUCTION

In March 2019, *The Lancet Infectious Diseases* published data from a population-based survey conducted by Vinck and colleagues in the Democratic Republic of the Congo (DRC). The study suggests that the inhabitants of eastern DRC actively avoided medical care and Ebola vaccination because they did not believe Ebola virus was real.[1] International media outlets soon reported the findings and reinforced a narrative that people suffering from Ebola virus disease (EVD) may blame their own *false* beliefs for the outbreak's spread. In the following months, we observed how this narrative of mistrust circulated among members of the media, the academy, health ministries and frontline response teams, reinforcing a particular paradigm of causality in the spread of Ebola that obscured the structural determinants of health.

There are many reasons that conclusions like those presented in *The Lancet Infectious Diseases* come to be widely reported and referenced. Analyses that attempt to isolate phenomena like 'trust' and 'belief' as measurable facts simplify complex social, political *and* epidemiological dynamics into fungible units that are easy to comprehend. In attributing disease transmission to things like 'culture', 'misinformation' and 'conspiracy theories'—as if these are spontaneously arising social forces that lead people in faraway places to act in unexpected ways—these studies offer a form of discussion that is easily engaged and circulated. However, by analytically omitting the historical and political determinants of the Congo's contemporary political situation—the very factors responsible for the 'levels' of trust in a violent, impoverished postcolonial context—these studies neglect a different set of empirical questions about the 'geographically broad and historically deep'[2] power relations that have contributed to the Ebola outbreak.[3] In so doing, such studies inadvertently relegate consideration of the historical antecedents of Congolese 'lack of trust' to outside the domain of 'valid' public health research, consideration and action.

A detailed analysis of how these historical forces become embodied as viral disease is beyond the scope of this study (and we have conducted such analyses elsewhere).[4–7] Rather, in this article, we argue that epidemiological studies that claim to capture the social dynamics of disease transmission in health-seeking behaviours all too readily serve as a smokescreen that enables and perpetuates ongoing structural inequities—notably, by omitting consideration of global power relations, colonial history and contemporary extractive political economies.

Our perspective is shaped by extensive experience conducting anthropological research in West Africa and the DRC, as well as clinical work during the Ebola outbreaks in both places. First, we will offer an alternative way of reading the issue of 'mistrust'. Next, by examining another major study on the dynamics of Ebola transmission in Sierra Leone, we will consider how predominant forms of epidemiological research effectively cause awareness of relevant historical—and continued economic—predation to disappear. Finally, we will offer some suggestions for what we call 'epistemic reconstitution' in the field of epidemiology. Ultimately, our stance is that neglecting histories of power relations and extraction in the study of global health crises

is not merely an act of passive, neutral omission; *such neglect constitutes an active reinscription—and therefore legitimation—of global health inequities along colonial lines.*

INTERPRETIVE INJUSTICE

Epidemiological studies of health-seeking behaviours conducted during the Ebola outbreaks in West Africa and Great Lakes region have rarely included an analysis of the historical sources of these countries' poverty or poor health systems. Without this history, mistrust is often portrayed as a result of 'misinformation', 'corruption', 'superstition' or simply irrationality. Such studies mystify the outbreaks' historical and geopolitical antecedents while confining the transmission of Ebola to a causal pathway defined by 'lack of trust→non-compliant actors→EVD'.[8] The evident solution, then, is to remedy this mistrust with proper health messaging and community 'outreach'.

When one juxtaposes a population's mistrust with a long-running history of exploitation and violence, mistrust begins to look less like a rational calculation based on misinformation and more like an inclination, a cognitive tendency[9] or an adaptive disposition (ie, habitus[10] towards eluding depredation[11]; that is, trust is not simply a dichotomous variable, with mistrust representing an absence (or even an excess of negative) value. Centuries of violent abuse, from slaving[12] to contemporary conflicts and predatory resource extraction,[13] all come to bear on shaping how diverse peoples relate to the powers that be, particularly when those representatives of power arrive with instructions for how to behave properly. Grounded in our experience with patients and ethnographic interlocutors in both the DRC and West Africa, we have come to appreciate alternative viewpoints, one of which is that mistrust may serve as a practical way of engaging with the 'history and ongoing effects of atrocities inflicted on African people, particularly when committed by non-Africans'.[14] Mistrust, as such, represents one mediator among many in a determinative web of human rights abuses that stretches back in time and across the region, linking the DRC and West Africa to distant continents.[8]

From this perspective, studies like the one described earlier lend themselves to what we consider 'interpretive injustice'[15] by (1) denying mistrust as a valid critique of the colonial legacies that persist to this day and (2) instantiating logics of causality that obscure how centuries of abusive power dynamics factor into contemporary public health emergencies.[4 8 16 17] While some researchers may counter that the tendency to conduct proximal, synchronic analyses is a consequence of available data and epidemiological research methods, we will show further that some quantitative social-science researchers have already begun to parameterise historical and geopolitical factors in an attempt to fashion an epidemiological inquiry capable of grappling with historical social forces.

EMPIRICISM IN THE SERVICE OF POWER

In most public health studies, colonial and neocolonial histories are not only *left out* but actually made *to disappear* through the analytics and vocabulary of epidemiological science. Take for example a 2016 study published in the *New England Journal of Medicine*, which presented data from the 2013–2016 Ebola outbreak in West Africa and concluded that approximately 20% of individuals (ie, 'superspreaders') generated 80% of cases of EVD.[18] We do not doubt the descriptive accuracy of the study; we trust the math and the observations that the virus moved through communities in such a pattern. We do, however, want to pause to ask: Who benefits from such an interpretation?

What initially looks like a benign set of statistics compiled by public health experts takes on a different hue when we share its language and framework with those directly suffering the epidemic. Taking the term superspreader, we asked interlocutors in the DRC what they thought, in the midst of the outbreak, and we took the question back to Ebola survivors in Sierra Leone and Liberia.[5] These community members directly affected by EVD all found the term inappropriate. They did not deny that one infected individual could subsequently infect multitudes; rather, they took issue with how the term singled out their friends and family without attending to the roles of government, international aid organisations and private companies. Indeed, some interlocutors flipped the premise, agruing that their governments be held to account as superspreaders, given widespread corruption. Others singled out foreign corporations; for instance, one man in Liberia responded that 'Firestone was the superspreader, since their lobbying prevented us from getting a tire factory' which might have helped fund a more functional health system and prevented iatrogenic transmissions.[8] The 'holocaust of slavery'[14] also came up in many conversations, and one man suggested that, even with extensive aid, elites alone would profit.[5 19] When asked about the mistrust narrative directly, common replies echoed those reported by journalist Amy Maxmen: 'People think this is just another thing brought from outside to kill'.[20]

This is not simply a misunderstanding or a lack of generosity to the authors of the *New England Journal of Medicine* piece on the part of West Africans and the Congolese. Most of our interlocutors are well aware of the good intentions of researchers dedicated to improving the health of populations. Yet they highlight how terminology, like superspreader, reinforces a paradigm unsuited for analysing structural harms. With our interlocutors, we find it fair to say that equating superspreader with individuals alone 'perniciously diverts us from structural determinants of Ebola virus transmission by positing *bounded individuals* and *their unconstrained, calculating agency*…as the engines of transmission'.[21] Indeed, were we to focus on behaviour change, it might be more appropriate to place the burden of such cognitive adjustment on the

architects and beneficiaries of extractive economies rather than on patients with Ebola.[22]

It is unlikely one will find an article from the WHO describing multinational corporations (eg, mining companies) as superspreaders, since conventional epidemiologists would likely deem such an analysis 'political' or 'unscientific'. Those mining companies continue their predatory accumulation unchecked,[6] contributing to the underdevelopment of health and other public service systems, bolstered by research paradigms that fixedly construe them as outside the domain of 'evidence-based' global health research or action. All the while, individual West Africans and Congolese remain acceptable foci of attention in epidemiological models, linking agency and, by implication, culpability. This is a choice, and it is one we make time and again, often unwittingly. (Perhaps, more accurately, it is our own cultural predisposition, cognitive tendency or habitus.)[10]

There is no shocking insight here other than that our ordinary practices readily locate blame on those who already endure the brunt of a grave, historic insult. Just as a family in the DRC inherits a colonial legacy that may favour mistrust, we well-compensated researchers and clinicians are not immune to legacies of thought and behaviour which sought to justify poverty and inferiority (ie, coloniality)[23–25]; that is, those who are tasked with producing knowledge about the world end up supporting an ideology that buttresses dominant economic interests: one that has and continues to benefit from neocolonial political economies.[26] Without giving analytical consideration to how sociohistorical forces become embodied as pathology,[27] authors of studies like those described previously unintentionally function as 'transfer mechanisms'[28] for the neoliberal logics of predatory accumulation.[8 11] It is all too easy for us to keep diverting the public's gaze from the historical and ongoing plunder of places like the DRC when diversion is part of the research design.

THE POSSIBILITY OF EPISTEMIC RECONSTITUTION

Though modest in our impact, we as a community of engaged researchers may enact a degree of epistemic reconstitution; that is, we can and should endeavour to improve the type of evidence we use and the knowledge we produce. Lowes and Montero offer an example of such epistemic reconstitution in their work on human African trypanosomiasis (sleeping sickness) in French Equatorial Africa. The authors draw on 30 years of colonial records collected by the French military in Congo-Brazzaville to demonstrate that the historical exposure to colonial medical campaigns correlates with lower levels of trust in the medical establishment today. Why the lower levels of trust? The answer is not definitive, but the colonial medical campaigns consisted of maltreatment ranging from forced lumbar punctures to excessive use of aminophenyl arsonic acid (atoxyl), an arsenic-containing compound of middling efficacy which left 20% of patients blind.[29]

While they recapitulate the methodological individualism and rational agency models that are pervasive in public health, Lowes and Montero may serve as an example of how public health research may be able to parameterise historical forces at play in how people relate to medical care today. The effort involved in this study was no doubt laborious, combining the archival with the classically epidemiological, yet the first effective studies in epidemiology came from curiosity about how disparate, heretofore unrelated occurrences hang together in a broader network of cause and consequence. In another innovative example, Alsan and Wanamaker relate contemporary health behaviours in Alambama to the Tuskegee experiments that began in 1932.[30] They therefore corroborate the contention that legacies of racist legal and medical systems are essential to consider in order to understand current relationships between communities and authorities—medical or otherwise. In short, mistrust is not an unprovoked phenomenon, and remedying its origins is not simply a matter of proper education.

Ultimately, such epistemic reconstitution could shape the strategies deployed by public health officials in an outbreak response. Introducing 'predatory and extractive resource accumulation' as a determinant of Ebola virus transmission *and* mistrust might pave the way for linking community outreach programmes to cash transfers or other forms of 'reparative reconstitution of capital'. Moreover, we hope epistemic reconstitution might help catalyse greater attention to redressing the historical and contemporary wrongs for which many of us hold responsibility, in particular, through nascent reparation campaigns.

CONCLUSION

Epistemic reconstitution may be challenging to accomplish, and it may fail in the face of funders who would rather not face the implications of looking beyond the individual as a vector of disease, since this could question the very accumulation of wealth they depend on.[31] Nonetheless, those of us who take on the task of explaining to the world why they are sick are in danger of becoming something more than 'prisoners of the proximate' (ie, methodologists who understand the determinants of human health in terms of downstream, individual-level risk).[32 33] Without change, we risk becoming the *apparatchiki*—the agents of the apparatus—of global health apartheid by decoupling analyses of power from disease dynamics.[34]

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