

AMA Journal of Ethics®

January 2020

Volume 22, Number 1: E1-65

Culture, Context, and Epidemic Containment

From the Editor

- Responding to Global Public Health Crises 3
Abraar Karan, MD, MPH, DTM&H

Case and Commentary

- How Should Public Health Officials Respond When Important
Local Rituals Increase Risk of Contagion? 5
Esther Mokuwa, MSc and Paul Richards, PhD, MA

- How Should Clinicians Integrate Mental Health Into
Epidemic Responses? 10
Shantanu Srivatsa and Kearsley A. Stewart, PhD

- How Should Clinicians Respond to International Public Health
Emergencies? 16
Abbey Lowe, MA, Angela Hewlett, MD, MS, and Toby Schonfeld, PhD

Medical Education

- Five Things Students and Clinicians Should Know About
"Biocontainment" 22
Helen Stanton Chapple, PhD, RN, MSN, MA

In the Literature

- How Should the WHO Guide Access and Benefit Sharing During Infectious
Disease Outbreaks? 28
Nicholas G. Evans, PhD, Kelly Hills, and Adam C. Levine, MD

Health Law

- When Are Vaccine Mandates Appropriate? 36
Carmel Shachar, JD, MPH and Dorit Rubinstein Reiss, LLB, PhD

State of the Art and Science

- Making Emergency Use of Experimental Vaccines Safer** 43
Archana Asundi, MD and Nahid Bhadelia, MD

Policy Forum

- How Should Global Health Security Priorities Be Set in the Global North and West?** 50
Abraar Karan MD, MPH, DTM&H

Medicine and Society

- What Should Health Science Journalists Do in Epidemic Responses?** 55
Katherina Thomas and Alpha Daffae Senkpeni

Art of Medicine

- Burnout** 61
Matt Heenan
- Worlds Apart** 63
Tamera Means, MD, MHS

Podcast

- Ebola Responses in Colonial Context: An Interview With Dr David Heymann and Dr Christy Rentmeester**

AMA Journal of Ethics®

January 2020, Volume 22, Number 1: E3-4

FROM THE EDITOR

Responding to Global Public Health Crises

Abraar Karan, MD, MPH, DTM&H

Epidemic outbreaks such as Ebola, dengue, Zika, measles, and influenza have all made international headlines within the last few years. Data suggest that epidemics are increasing in frequency largely as a result of global interconnectedness, which allows viruses to travel from one region to another in just a few hours.¹ Because epidemics are extremely complex, they require coordinated responses across many disciplines. Not only biology and medicine but also anthropology and sectors such as international relations and defense are needed to understand and treat these diseases. It is no surprise that, no matter where one lives, epidemics matter or at least should be of concern. In 2014, an Ebola outbreak in West Africa quickly crossed into the United States and Europe,² and global spread of influenza occurs annually. Navigating ethical dilemmas raised during epidemics is central to good decision making and managing responses effectively, so this issue of the *AMA Journal of Ethics* considers them from a variety of disciplinary perspectives.

There are several sets of ethical questions. Since a goal of epidemic response is to contain disease while minimizing harm, one set of ethical questions explored in this theme issue considers whether and when violating individual freedoms is ethically justifiable to motivate safety for a majority. Another set of questions considers the nature and scope of [response teams' obligations](#) to ensure that iatrogenic consequences of response strategies are addressed. Roles of political borders in epidemic responses are also interrogated in this issue. For example, whether, when, and how international experts should cross borders can be informed by colonial legacies, influence locals' [trust in public health efforts](#), and undermine [containment efforts](#) in some regions. As a global governing body and a leader in pandemic responses, the World Health Organization and its policies, practices, and publications can guide day-to-day operations during epidemics, including in the ongoing (from 2018) Ebola outbreak in the Democratic Republic of the Congo (DRC). Decisions about which criteria should be used to consider when it is just to use [experimental vaccines](#) and how to prioritize limited resource expenditures are also critical. Questions related to communication and how information is transmitted when members of a community are at risk are also considered in this issue, as are roles of [international journalists](#) when offering the world accurate stories of what happens and when.

Leading experts in global health, anthropology, international security, infectious disease, journalism, and law contribute to this collection of articles exploring the complex intersections of ethics and epidemic response strategy. In doing so, these authors pursue a better understanding of what constitutes good micro-level and macro-level decision making during global health crises.

References

1. Madhav N, Oppenheim B, Gallivan M, Mulembakani P, Rubin E, Wolfe N. Pandemics: risks, impacts, and mitigation. In: Jamison DT, Gelband H, Horton S, et al, eds. *Disease Control Priorities: Improving Health and Reducing Poverty*. 3rd ed. Washington, DC: International Bank for Reconstruction and Development; World Bank; 2017:315-346.
2. Uyeki TM, Mehta AK, Davey RT Jr, et al. Clinical management of Ebola virus disease in the United States and Europe. *N Engl J Med*. 2016;374(7):636-646.

Abraar Karan MD, MPH, DTM&H is an internal medicine resident in the Doris and Howard Hiatt Residency in Global Health Equity and Internal Medicine at Brigham and Women's Hospital in Boston, Massachusetts.

Acknowledgements

Thanks to Ingrid Katz for her mentorship in the development of this issue.

Citation

AMA J Ethics. 2020;22(1):E3-4.

DOI

10.1001/amajethics.2020.3.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

CASE AND COMMENTARY

How Should Public Health Officials Respond When Important Local Rituals Increase Risk of Contagion?

Esther Mokuwa, MSc and Paul Richards, PhD, MA

Abstract

During the 2014-2015 Ebola epidemic in Sierra Leone, people were required by law to call a trained “safe burial” team to dispose of the body of a person who had died from Ebola. It took days for a team to arrive, however, due to limited resources and rural travel obstacles, so some villagers felt obliged to bury their loved ones themselves. Even with timely arrival of a team, there can be cultural priorities that deserve attention. One man’s case discussed in this article suggests the need for Ebola responders to consider villagers’ perspectives and possibilities for compromise.

Case

Dr R is a physician working in the Democratic Republic of the Congo tasked with creating a quarantine policy for the bodies of Ebola victims, given high transmission rates from bodily fluid exposures. He receives reports of a confirmed Ebola death in a nearby village. Upon arriving with the Ebola response team, he is met by the wife and brothers of the deceased man. They refuse to allow the man’s body to be removed according to safety protocol. They explain that his body cannot be buried without first undergoing a religious cleaning by the family and a religious leader. Dr R explains that touching the body is dangerous and can easily lead to others contracting Ebola. The man’s family insists that he should not be buried without the religious ritual. How should Dr R reconcile the cultural importance of honoring local burial rituals with his obligation to prevent the spread of Ebola?

Commentary

The anthropologist Mary Douglas devoted her career to explaining that moral arguments derive from social context,¹ and because social life is complex and open-ended, there will always be conflict between competing values. It was a basic concern of anthropology, she argued, to understand how human groups accommodate conflicting ethical demands.² This article applies Douglas’ insight to safe burial protocol implementation during the 2014-2015 Ebola epidemic in Sierra Leone and is based on our experience living and working there.

Mutual Care Conflicts With Containment

In rural communities at the edge of a tropical forest region in Upper West Africa, villages are small and can be interconnected by marriage ties, so the

welfare of family members linked by marriage is prioritized as an ethical value among members of these communities. Mutual support sustains their way of life, and visiting those who are ill, dying, or deceased reinforces social solidarity. Ebola virus disease (EVD) challenges the moral basis of local social life in such communities, since infection can spread when one cares for the sick and prepares bodies for funerals. In other words, infection containment requires that one refrain from caring for the sick in moments of patients' extreme need and from preparing corpses for dignified burial. Infection containment thus presents many people with a conflict between 2 social obligations: to care for others as an expression of local interfamily solidarity and to preserve the community by helping control the spread of disease.

National and international Ebola responders stressed infection control, key to which is early [isolation of patients](#) with EVD. But early EVD symptoms can look like [malaria](#), also widespread in the region, and thus can be hard to accurately diagnose early. Later onset symptoms of EVD (vomiting, diarrhea, and sometimes bleeding, for example) are optimally managed in specialized care facilities—typically far from where patients live, especially if rehydration therapy is applied—to improve patients' chances of survival. An instinct of many patients' family members was to follow the patient to a care facility and offer support by preparing food and touching or talking to the patient, for example. But when a patient with EVD was brought by ambulance to a distant treatment center, personal care was compromised, if not impossible. Furthermore, when a transported patient receiving specialized care died, it was rarely possible for family members to be notified in time to take part in that person's burial.

How Ethnography Informed Compromise

Sierra Leone was one of the worst-affected countries in the 2014-2015 West African Ebola epidemic.³ Responders deployed modern media resources to impart (Western, allopathic) messages about biosafety that implied that "traditional" approaches to caring for EVD patients and burying deceased patients were backward or barbaric. Such messaging was backed by the Sierra Leone government, which threatened fines and imprisonment and insisted upon family members' exclusion from all burials throughout the country, even though few deaths at that time were due to EVD. Families were prevented from washing and dressing corpses and had to wait, sometimes for days, for a trained burial team to arrive. Out of fear or nervousness, some teams heaved corpses quickly into graves with poles. Mourners were held at a distance or forbidden from witnessing burials at all. Outraged, some people resisted on having loved ones with EVD infections transported to care centers and began hiding and burying bodies of deceased patients.

One young man in a village in eastern Sierra Leone, who had attended his mother as she died of EVD, viewed it as simply unforgiveable not to clean and dress her body. She had given him life, and he saw himself as obliged to stand by her in death. So he performed the ritual alone and quietly buried her; he informed no one and accepted that he would probably become infected with EVD and die. To protect others from his probable infection and to avoid incarceration in an Ebola treatment facility, he left his village, planning to hide in the bush until EVD symptoms emerged; if they did, he would die alone.

After experiencing no symptoms, he reported to a health center for an EVD blood test. His test was negative. Although this man's story is obviously clinically important, from an anthropological perspective, it suggests the importance of compromise between needs of responders to contain disease and needs of local people to perform burial rituals of cultural significance.

Anthropological Foundations of Improved Ebola Care

Possibilities for compromise emerged when anthropologists helped gain a wider hearing for local people's stories and ethical perspectives.⁴ One result of anthropologists' publicizing of stories involving ethical dilemmas was to shift responders' views about burials. As a result, Sierra Leone's national protocol on safe burial was amended to "safe and dignified" burial.⁵ Pastors and imams were engaged to officiate at the graveside, and families were allowed to attend. Another result of anthropologists' roles in the 2014-2015 epidemic was that EVD treatment became localized. That is, large and distant Ebola treatment centers were supplemented by smaller, local community care centers (CCCs)⁶ where all diseases were treated. This change encouraged earlier reporting of EVD symptoms and testing. Moreover, many CCC staff were recruited from local communities and thus were known to patients. This familiarity enhanced trust, eased family access to patients, enabled better reporting about patients' progress, and facilitated provision of home-prepared food for patients. Even when family members couldn't enter the "red zone" to be at a patient's side, they could see the patient and talk through open sides of the tents. Family presence helped some patients survive. Even when the CCC reported deaths by phone, loved ones were on hand and able to gather for burial.

Although CCCs improved family access to patients, responders began to recognize that not all communities had working phones from which to call for an ambulance or roads that an ambulance could even traverse. As a solution, poster-based information, reinforced by radio broadcasts, helped family members learn what to do for a patient while waiting for an ambulance.⁵ Family members continued to care for patients while also protecting themselves with plastic bags and coats worn backwards. They also attempted to mitigate risk of contracting EVD by having one person care for the patient while others supported the carer.^{3,7}

Contextualizing "Biosafety"

Allowing more family involvement in caregiving changed public attitudes towards the epidemic response effort significantly. Communities took ownership of local care facilities and EVD itself. Caregiving and burial preparation were never regarded as "safe," so recruiting and training local burial teams remained as important as allowing family members to assume active roles in burial. One lesson is that competing cultural and public health values need to be balanced. Shouting down pleas to perform culturally important death and burial practices in the name of biosafety was not helpful. The 2014-2015 Ebola epidemic in West Africa demonstrated the necessity of compromise between conflicting values and the role of anthropology in implementing compromise.

References

1. 6 P, Richards P. *Mary Douglas: Understanding Social Thought and Conflict*. New York, NY: Berghahn; 2017.
2. Douglas M. Witchcraft and leprosy: two strategies for rejection. In: Douglas M. *Risk and Blame: Essays in Cultural Theory*. London, UK: Routledge; 1992:83-101.
3. Richards P. *Ebola. How A People's Science Helped End an Epidemic*. London, UK: Zed Press; 2016.
4. Ebola Response Anthropology Platform website. <http://www.ebola-anthropology.net/>. Accessed May 30, 2019.
5. Concern Worldwide. Concern Sierra Leone—Safe and Dignified Burials Programme. https://ec.europa.eu/health/sites/health/files/ngo_award/doc/summary_report_concernworldwide_en.pdf. Accessed October 14, 2019.
6. Oosterhoff P, Mokuwa E, Wilkinson A. Community-based Ebola care centres: a formative evaluation. Ebola Response Anthropology Platform. http://www.ebola-anthropology.net/wp-content/uploads/2015/07/Community-Based-Ebola-Care-Centres_A-Formative-Evaluation1.pdf. Published 2015. Accessed May 30, 2019.
7. Centers for Disease Control and Prevention. Steps to protect from Ebola while you wait for help. https://www.cdc.gov/vhf/ebola/pdf/2018/english/Protect-from-Ebola-While-You-Wait-Flipbook_English_P.pdf. Published 2015. Accessed May 30, 2019.

Esther Mokuwa, MSc is an honorary research associate at Njala University in Njala, Sierra Leone, and an external PhD candidate at Wageningen University. In 2014 and 2015 she undertook extensive field surveys of local responses to the epidemic of Ebola virus disease and has co-written papers on the Ebola epidemic in the *Lancet* and *PLOS Neglected Tropical Diseases*.

Paul Richards, MA, PhD is an adjunct professor at Njala University in Njala, Sierra Leone, and an emeritus professor of technology and agrarian development at Wageningen University. He is also the author of *Ebola: How a People's Science Helped End an Epidemic* (Zed Books, 2016).

Editor's Note:

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2020;22(1):E5-9.

DOI

10.1001/amajethics.2020.5.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

CASE AND COMMENTARY

How Should Clinicians Integrate Mental Health Into Epidemic Responses?

Shantanu Srivatsa and Kearsley A. Stewart, PhD

Abstract

The 2014 Ebola epidemic in Sierra Leone and the current outbreak that began in 2018 in the Democratic Republic of the Congo generated numerous mental health crises that remain unaddressed by global standard infectious disease protocols. This article explores how responders should integrate mental health care into standard Ebola care.

Case

Dr M, an infectious disease physician, has been treating Ebola patients in the Democratic Republic of the Congo (DRC) for several months. The epidemic has just recently reached a positive turning point: as more treatment units have been opening, more patients have been surviving Ebola virus disease (EVD). However, Dr M has learned that some survivors of EVD are shunned or not allowed to return to their communities when they recover because of fears that they still have Ebola. Also, some EVD survivors experience hallucinations, nightmares, and other symptoms of posttraumatic stress from their Ebola illness experiences. One of Dr M's patients cries, "You treat us, but we do not have anywhere to go!" She describes recurrent nightmares in which men wearing white personal protective equipment and suits surround her, and she awakes sweaty with palpitations. She states that she feels down, uninterested in activities she used to enjoy. Dr M's international health organization has not typically deployed psychiatrists, psychologists, or other mental health professionals to help address patients' Ebola trauma experiences and symptoms.

Commentary

Epidemic response strategies typically involve infection control, health systems strengthening, and other disease containment strategies. However, intense focus on pathogen transmission can lead responders to overlook trauma and psychosocial damage to individuals and communities during and following an epidemic.¹ Weak mental health care infrastructure can be exposed by disasters, leaving responders ill equipped to provide appropriate care.^{1,2,3,4} Untreated, mental illness can lead to long-lasting health consequences and contribute to stigmatization of survivors.^{1,5,6} Furthermore, some mental health effects can be iatrogenic consequences of treatment or containment protocols, such as isolation, quarantine, or exposure to novel equipment such as personal protective equipment (PPE), particularly biohazard suits.^{7,8} Following the 2014 Ebola outbreak in West Africa, the prevalence of reported symptoms of mental health disorders was extremely

high, with 48% of survey respondents reporting at least one symptom of depression or anxiety in 2015.¹

Clinicians volunteering as outbreak responders must anticipate working in health systems unable to provide even minimal mental health care. But without adequate training, clinician volunteers attempting to provide ad hoc mental health care could cause additional harm to a patient.² This commentary reviews reasons for mistrust of government and psychosocial consequences of EVD and argues that Dr M—and all clinicians treating Ebola patients in the DRC—should be trained to integrate at least basic mental health care into epidemic response practice.

Mistrust and Historical Trauma

The World Health Organization (WHO) response to the 2014 Ebola epidemic in Sierra Leone was widely criticized as lacking timeliness and leadership.³ By 2016, there were over 3900 deaths and 14 100 cases in Sierra Leone, and many individuals had experienced long-lasting psychological symptoms.¹ Moreover, the ongoing Ebola outbreak is complicated by ongoing armed conflict in the eastern DRC.⁹ Violence has hindered containment efforts; many new cases have arisen in conflict zones.¹⁰

Political instability has exacerbated both mistrust of government and the spread of misinformation. Indeed, a *Lancet* survey of adults in the DRC found that though the vast majority of respondents believed in the efficacy of vaccines, roughly two-thirds reported that they would not accept the Ebola vaccine, largely due to mistrust of its safety or efficacy.¹⁰ Those living in war zones also suffer conditions ranging from physical trauma to depression and posttraumatic stress disorder (PTSD).^{11,12,13} These mental health conditions, when combined with Ebola and military and paramilitary reinforcement of corporate interests, further undermine trust in public health infrastructure and the capacity to promote good health outcomes and to contain disease.^{14,15}

Responders should consider the clinical and ethical relevance of legacies of violence perpetrated by **colonial powers** in Ebola-endemic areas. Because countries that were once colonizers of the DRC are perhaps among those now currently aiding Ebola epidemic relief efforts, old legacies of mistrust are exacerbated when international donors distribute nearly all available experimental vaccines to international health care workers rather than local people.¹⁶ This history of exploitation and inequity underscores the importance of asking questions about the intentions of international actors and what they stand to gain in the DRC.

Ebola and Psychosocial Context

As in the case, some patients who survive EVD are shunned and thus isolated and stigmatized.^{5,6} Factors exacerbating stigmatization of EVD survivors in Ebola-endemic areas include political upheaval and cultural beliefs about EVD.^{5,6,10,17,18,19} Even when EVD patients survive, entrenched stigmatization and mental illnesses arising from treatment suggest the need to build clinicians' capacity to respond to psychosocial dimensions of EVD and Ebola care.

iatrogenic effects of EVD and EVD survival also deserve attention from a psychosocial perspective. Due to the high fatality rate of EVD, some clinicians fear patients, which can lead them to minimize physical contact with EVD patients, consequently diminishing the quality of care such patients receive. When patients feel shunned by clinicians, their fear and mistrust can be exacerbated, as demonstrated in the case by the patient who reported nightmares and recurrent fears of men in white PPE Ebola treatment suits. Although the WHO created a Mental Health Gap Action Programme in 2010 for use in low-resource settings,²⁰ this guide does not sufficiently emphasize the importance of culturally appropriate responsiveness, epidemic-specific challenges in global health care delivery, or “upstream” prevention factors that could help decrease the need for mental health services.

Culturally appropriate responsiveness to mental illnesses generated or exacerbated by epidemics such as Ebola is critical to mitigating local persons’ distrust of international clinicians. Dr M, for example, could integrate mental health care into treatment for patients with EVD. Toward this end, Dr M should [assess patients’ psychological state](#) and identify key stressors. Rapid mental health diagnostic tests could help clinicians like Dr M identify and assess those patients in need of mental health support.^{11,17,21} A critical component to diagnosing mental illness is employing questionnaires written and validated using culturally specific terms pertaining to an illness. For instance, words like *depression* or *posttraumatic stress disorder* might not be understood or elicit valid responses from patients, so translating mental illness symptoms into appropriate and meaningful language is essential to being able to help patients.

Helping Responders Help Patients

Sensitivity to cultural factors could help responders like Dr M address stigma and help patients cope with stress.¹⁹ Accordingly, workshops led by specialists could be offered to help responders implement referral pathways and to make support services available. Treatment for EVD should always include access to follow-up mental health care (therapy and medications) as needed. If mental health service infrastructure is lacking, responders should be paired with mental health caregivers at an Ebola treatment site to meet the full spectrum of patients’ needs. Mobile [apps](#) or text messaging can also be helpful when screening for mental illness^{21,22}; enabling wider use of these approaches in international settings could help identify and treat symptoms like those experienced by the patient in the case. Prioritizing EVD patients’ short-term and long-term general health, including mental health outcomes, must be how good Ebola care is defined.

In the ongoing 2018 epidemic, as well as in future Ebola epidemics, international organizations, such as the one for which Dr M works, should seek international and local community support for these priorities. They should also design culturally appropriate educational messages for both Ebola and mental health care and employ responders trained to contain pathogens and psychological trauma.²³ To bolster underlying infrastructure for culturally appropriate health service delivery, it is critical to establish and support community-based partnerships with local stakeholders. Community input in stakeholder relationships can subserve better resource allocation and service

delivery prioritization.^{24,25} Being transparent about priorities, seeking international and local community support in implementing them, and training responders are 3 ways to improve Ebola care in the DRC.

Conflict and political violence have exacerbated the 2018 outbreak, and mistrust of responders like Dr M must be taken into account in outbreak responses.¹⁰ Both Ebola and political strife contribute to mental illness, including depression, PTSD, and related psychosocial disorders.¹⁸ Although Dr M cannot fill gaps in larger infrastructure alone, understanding how mental illnesses are expressed among patients in a specific context can motivate more robust international responses to affected patients and communities.

References

1. Jalloh MF, Li W, Bunnell RE, et al. Impact of Ebola experiences and risk perceptions on mental health in Sierra Leone, July 2015. *BMJ Glob Health*. 2018;3(2):e000471.
2. O'Leary A, Jalloh MF, Neria Y. Fear and culture: contextualising mental health impact of the 2014-2016 Ebola epidemic in West Africa. *BMJ Glob Health*. 2018;3(3):e000924.
3. Wenham C. What we have learnt about the World Health Organization from the Ebola outbreak. *Philos Trans R Soc Lond B Biol Sci*. 2017;372(1721):20160307.
4. Bell BP. Overview, control strategies, and lessons learned in the CDC response to the 2014-2016 Ebola epidemic. *MMWR Suppl*. 2016;65(3):4-11.
5. James PB, Wardle J, Steel A, Adams J. Post-Ebola psychosocial experiences and coping mechanisms among Ebola survivors: a systematic review. *Trop Med Int Health*. 2019;24(6):671-691.
6. Lötsch F, Schnyder J, Goorhuis A, Grobusch MP. Neuropsychological long-term sequelae of Ebola virus disease survivors—a systematic review. *Travel Med Infect Dis*. 2017;18:18-23.
7. Hawryluck L, Gold WL, Robinson S, Pogorski S, Galea S, Styra R. SARS control and psychological effects of quarantine, Toronto, Canada. *Emerg Infect Dis*. 2004;10(7):1206-1212.
8. Johal SS. Psychosocial impacts of quarantine during disease outbreaks and interventions that may help to relieve strain. *N Z Med J*. 2009;122(1296):47-52.
9. Barry A, Ahuka-Mundeke S, Ahmed YA, et al. Outbreak of Ebola virus disease in the Democratic Republic of the Congo, April-May, 2018: an epidemiological study. *Lancet*. 2018;392(10143):213-221.
10. Vinck P, Pham PN, Bindu KK, Bedford J, Nilles EJ. Institutional trust and misinformation in the response to the 2018-19 Ebola outbreak in North Kivu, DR Congo: a population-based survey. *Lancet Infect Dis*. 2019;19(5):529-536.
11. Bayer CP, Klasen F, Adam H. Association of trauma and PTSD symptoms with openness to reconciliation and feelings of revenge among former Ugandan and Congolese child soldiers. *JAMA*. 2007;298(5):555-559.
12. De Jong J. *Trauma, War, and Violence: Public Mental Health in Socio-Cultural Context*. New York, NY: Springer Science & Business Media; 2006.

13. Mels C, Derluyn I, Broekaert E, Rosseel Y. The psychological impact of forced displacement and related risk factors on Eastern Congolese adolescents affected by war. *J Child Psychol Psychiatry*. 2010;51(10):1096-1104.
14. Ebola Gbalo Research Group. Responding to the Ebola virus disease outbreak in DR Congo: when will we learn from Sierra Leone? *Lancet*. 2019;393(10191):2647-2650.
15. Tariq A, Roosa K, Mizumoto K, Chowell G. Assessing reporting delays and the effective reproduction number: the Ebola epidemic in DRC, May 2018-January 2019. *Epidemics*. 2019;26:128-133.
16. Donovan G. Ebola, epidemics, and ethics—what we have learned. *Philos Ethics Humanit Med*. 2014;9(1):15.
17. Shultz JM, Baingana F, Neria Y. The 2014 Ebola outbreak and mental health: current status and recommended response. *JAMA*. 2015;313(6):567-568.
18. Hughes P. Mental illness and health in Sierra Leone affected by Ebola: lessons for health workers. *Intervention*. 2015;13(1):10.
19. Hewlett BS, Amola RP. Cultural contexts of Ebola in northern Uganda. *Emerg Infect Dis*. 2003;9(10):1242-1248.
20. World Health Organization. WHO Mental Health Gap Action Programme (mhGAP). http://www.who.int/mental_health/mhgap/en/. Accessed April 30, 2019.
21. Tomita A, Kandolo KM, Susser E, Burns JK. Use of short messaging services to assess depressive symptoms among refugees in South Africa: implications for social services providing mental health care in resource-poor settings. *J Telemed Telecare*. 2016;22(6):369-377.
22. Musyimi CW, Mutiso VN, Haji ZR, Nandoya ES, Ndeti DM. Mobile based mhGAP-IG depression screening in Kenya. *Community Ment Health J*. 2018;54(1):84-91.
23. Ali GC, Ryan G, Silva MJD. Validated screening tools for common mental disorders in low and middle income countries: a systematic review. *PLoS One*. 2016;11(6):e0156939.
24. Viswanathan M, Ammerman A, Eng E, et al. Community-based participatory research: assessing the evidence. *Evid Rep Technol Assess (Summ)*. 2004;(99):1-8.
25. Coughlin SS. Community-based participatory research studies on HIV/AIDS prevention, 2005-2014. *Jacobs J Community Med*. 2016;2(1):019.

Shantanu Srivatsa is a student in the Master of Science in Global Health Program at Duke University in Durham, North Carolina. His current research includes machine learning as a tool to predict traumatic brain injury outcomes, integrative research on sickle cell disease, and racial disparities in clinical trial access.

Kearsley A. Stewart, PhD is a Professor of the Practice in Global Health and in Cultural Anthropology at Duke University in Durham, North Carolina. She teaches global health research ethics at the graduate and undergraduate level, and her current work focuses on the ethics of arts-based research methodologies for health research in Africa.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2020;22(1):E10-15.

DOI

10.1001/amajethics.2020.10.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

CASE AND COMMENTARY

How Should Clinicians Respond to International Public Health Emergencies?

Abbey Lowe, MA, Angela Hewlett, MD, MS, and Toby Schonfeld, PhD

Abstract

This case analysis examines obligations health care workers have to support relief efforts when an infectious disease outbreak could impact us all. How clinicians, institutions, and local communities ought to balance increased need for global solidarity in response to global disease outbreaks with concerns of local stakeholders is one specific tension this article investigates. We explore how emphasizing global health solidarity in the face of highly hazardous communicable diseases can help mitigate global risk.

Case

Dr W is a hospital administrator at BB academic medical center in the United States. BB has a prominent global health program, and Dr V, an expert in epidemic responses, has expressed interest in working abroad with Médecins Sans Frontières (MSF—Doctors Without Borders) on the current Ebola outbreak. Upon returning from work in prior Ebola outbreaks, clinicians have been monitored in isolated Ebola units until it can be confirmed that they have not contracted the virus. Despite staff having been “cleared,” however, some BB patients worry about attending appointments or coming to a hospital where “some doctors and nurses have been around Ebola.” Even some members of BB’s staff have stated that they will not treat patients who have a disease as deadly as Ebola out of fear for their own safety. Concerned about bad publicity and media attention, the BB board of directors has asked Dr W to dissuade Dr V from continuing international work on Ebola containment, suggesting that “there are other important global health projects that don’t scare people so much.” Dr W wonders how to respond.

Commentary

Health care workers (HCWs) are holders of privileged knowledge and of the public’s trust; they have a sacred duty in society—that of healers. In return for the public’s trust, they owe a duty to care based on their fiduciary relationship to patients.¹ In the legal sense, the phrase *a duty of care* stems from a special relationship between a physician and his or her patient—a relationship that is voluntary and entered into by mutual agreement.² Certainly, this definition is clear when applied to a cardiologist treating a patient presenting at the hospital with chest pain. However, what is the obligation of an expert in epidemic responses, like Dr V, to those suffering from highly hazardous communicable diseases in the midst of an epidemic?

There is little consensus on the extent to which health care workers have a duty to provide health services in an outbreak or what that duty might entail.³ Explicating the duty to care in a public health emergency of international concern (PHEIC) comes with hurdles. The challenges stemming from a PHEIC might include: (1) difficulty in defining hospitals' obligations to multiple groups—employees, patients, and the community; (2) providing safe working conditions for HCWs; (3) operating in a health care system with different standards of care; and (4) providing compensation and time off for HCWs to travel to impacted areas.¹

Without clear formulation of the duty to care in a PHEIC, HCWs as well as academic medical center leadership may end up overwhelmed by the challenges of serving in an outbreak-afflicted area. Yakubu et al assert that there is not a professional duty to treat in these circumstances, only a moral one.⁴ Yet here we will argue that, given the landscape of outbreaks of international concern, Dr V's expressed interest and altruism in serving abroad are not merely issues of personal conscience; they exemplify the value of solidarity that institutions like BB academic medical center and society should encourage.⁵

Global Health Solidarity

British bioethicists Prainsack and Buyx define solidarity as an "enacted commitment to carry 'costs' (financial, social, emotional, or otherwise) to assist others with whom a person or persons recognize similarity in a relevant respect."⁶ Our shared vulnerability to highly hazardous communicable diseases (HHCDs)—diseases that only know the boundaries of biology and don't respect **national borders**—should incite a shared responsibility to fight an HHCD outbreak together.⁷ The similarity that exists between a patient at BB academic medical center and an individual living in the Democratic Republic of the Congo (DRC) is that both are increasingly united in their vulnerability to emerging threats. Consider a US citizen returning from a visit to the DRC on a full plane back to the US sitting in seat 52B. Two days later, a passenger who had been seated in 52A begins to feel nauseous. Ten days after returning to his home, the passenger who had been seated in 52C visits the emergency room with a high fever and vomiting. Even with safeguards, exposure can build exponentially. An outbreak in the DRC, if not contained, will spread to countries on different continents, just as it has spread to countries within Africa. Although the United States and Europe have been successful in treating patients with known Ebola virus disease (EVD) through airlifting them and treating them in specialized biocontainment units, these are limited resources.⁷ If exposures and known cases breach the limits of those resources, controlling the spread of EVD is likely to tax the US health care system and threaten the health security of the US population. The duty to care for those suffering on the other side of the globe may be strengthened by greater recognition of our shared vulnerability and a commitment to solidarity toward a shared threat. Solidaristic practices would entail taking action to care for those suffering abroad with the support of the government and institutions, just as if the outbreak were on US soil.⁸

Dr V's desire to serve in an area affected by the outbreak, putting her life at risk, demonstrates solidarity—to be in **solidarity with others** is to act on their

behalf and to accept the costs of doing so.⁸ However, her risk is not hers alone. Dr V's actions stand to affect BB's patients as well as the community at large. As such, BB academic medical center's board of directors is correctly concerned about the risk of exposure to current patients and assuaging fear of community members, who, along with BB patients and some staff, might perceive the ongoing work done by BB medical center's participating staff as a threat to their safety. BB patients and staff may be especially concerned about being exposed to Ebola by BB clinicians returning from working in the outbreak-affected area.

Health care institutions should have a strategy for managing the risk of exposure to patients and employees from returning staff who have worked in outbreak-afflicted areas, as it is possible to manage the risk of this exposure effectively. Clinical staff should be required to register their travel and prospectively commit to complying with Centers for Disease Control and Prevention guidelines for managing potential Ebola virus exposure⁹ on their return, as these guidelines have proven effective in US monitoring of health care professionals returning from EVD outbreak environments.¹⁰ With these controls in place, physical risks are manageable; they should not dominate the discourse about supporting international service.

Supporting HCWs' service in a PHEIC through organizations like MSF contributes to their safety and mitigates their risk of contracting disease. However, an additional concern for BB's board of directors is that the BB patient community feel adequately safeguarded; BB academic medical center upholds its reputation as a trusted institution in the community. Dr W should respond to BB's board of directors by providing a clear explanation of the physical risks to HCWs working with MSF and the likelihood of their contracting an HCCD. In addition, Dr W should detail a plan to mitigate the risk of exposure to patients along with a communication strategy designed to provide transparent responses to patients' concerns and to garner trust within the BB community.

Solidarity is often an implicit prerequisite among groups for the delivery and maintenance of important social infrastructures.⁷ Public health programs such as vaccination campaigns or routine water sampling—or infrastructure like the justice system—work on behalf of the public and are funded through the government. Solidarity could underlie the approach to global health threats, as academic medical centers with prominent global health programs, such as BB, could commit a portion of their funds to strengthening health care infrastructure in affected countries. If BB academic medical center's board of directors see the community as vulnerable to the threat of HHCDs, supporting a range of efforts to contain a disease might be easier to “sell” to their patients and community. BB academic medical center and hospitals who mobilize qualified HCWs to work in affected areas could not only meet the needs of desperate patients but also contain Ebola at its source, averting global risk.

Solidarity in Practice

Pursuing global health solidarity could be an aspirational component of a global health program's mission, but implementing it is not without difficulty

for academic medical centers. Supporting [health care workers who go abroad](#) to assist in mitigating an outbreak takes careful consideration on the part of academic medical centers concerning the risks employees may face—ranging from contracting HHCDs to potentially working amidst political instability and violence. For academic medical centers with global health programs, steps should be taken to ensure that staff members in the field are adequately supported and that the institution has staffing coverage, especially when sending a team of health care workers for an extended period of time.

Local support. Uncertainty surrounds the continued availability of medical evacuation for staff, and there may also be concerns regarding violence and civil unrest in Ebola-affected countries.¹¹ Dr V cannot be expected to shoulder this risk alone but rather should receive support from BB academic medical center, which might worry about whether it can adequately protect its employees. To minimize the risks and maximize the benefits of HCWs' service, academic medical centers and other institutions should require that HCWs who volunteer to serve do so only through established and qualified organizations and should help HCWs to inform themselves fully of all residual risks and uncertainties.⁵

Staffing coverage. BB academic medical center's commitment to support HCWs serving in an outbreak-afflicted area also requires consideration of the strain it will place on its staff and patients. Providing care in Ebola-affected regions can involve an extensive time commitment for clinicians—not only time spent deployed but also several days of training and sometimes several weeks postdeployment away from work for monitoring, if required.⁵ On the clinical side, Dr V's time away from work could increase BB clinicians' patient load, create strain on colleagues who are tasked with covering extra responsibilities, and jeopardize continuity of physician care. Although it will be necessary for academic medical centers to address these concerns, the number of HCWs willing and qualified to serve is small, and the strain on institutions and staff members is likely to be minor.⁵

Conclusion

In an editorial in the *Bulletin of the World Health Organization*, Flahault et al argue that respect for [human rights](#) and solidarity should be at the heart of each country's national security agenda; furthermore, the authors claim that these values are consistent with the motives of many people who provide health services in public health emergencies.¹² BB academic medical center and its leadership should consider how solidarity fits with the mission of the institution's global health program. Solidarity practices should be communicated to and reinforced within the institution and community. Such efforts can make inroads in garnering support from BB staff, patients, and community stakeholders in supporting HCWs willing to act on their sense of solidarity.

References

1. Thompson A. Bioethics meets Ebola: exploring the moral landscape. *Br Med Bull*. 2016;117(1):5-13.
2. Shensky ES. What is a healthcare provider's duty to care? *National Law Review*. October 19, 2015.

<https://www.natlawreview.com/article/what-healthcare-provider-s-duty-care>. Accessed on July 9, 2019.

3. Ruderman C, Tracy CS, Bensimon CM, et al. On pandemics and the duty to care: whose duty? Who cares? *BMC Med Ethics*. 2006;7:e5.
4. Yakubu A, Folayan MO, Sani-Gwarzo N, et al. The Ebola outbreak in Western Africa: ethical obligations for care. *J Med Ethics*. 2016;42(4):209-210.
5. Mello M, Merritt M, Halpern S. Supporting those who go to fight Ebola. *PLoS Med*. 2015;12(1):e1001781.
6. Prainsack B, Buyx A. *Solidarity: Reflections on an Emerging Concept in Bioethics*. London, UK: Nuffield Council on Bioethics; 2011.
7. West-Oram PGN, Buyx A. Global health solidarity. *Public Health Ethics*. 2017;10(2):212-224.
8. Uyeki TM, Mehta AK, Davey RT Jr, et al; Working Group of the US-European Clinical Network on Clinical Management of Ebola Virus Disease Patients in the US and Europe. Clinical management of Ebola virus disease in the United States and Europe. *New Engl J Med*. 2016;374(7):636-646.
9. Centers for Disease Control and Prevention. Interim US guidance for monitoring and movement of persons with potential Ebola virus exposure. <https://www.nalc.org/workplace-issues/body/2014-10-29-CDC-Update-on-monitoring-and-movement-of-persons-with-Potential-Ebola.pdf>. Updated November 28, 2014. Accessed May 28, 2019.
10. Stehling-Ariza T, Fisher E, Vagi S, et al. Monitoring of persons with risk for exposure to Ebola virus disease—United States, November 3, 2014–March 8, 2015. *MMWR Morb Mortal Wkly Rep*. 2015;64(25):685-689.
11. Mangan K. Universities curtail health experts' efforts to work on Ebola in West Africa. *Chron High Educ*. 2014;61(9):A12.
12. Flahault A, Didier W, Zylberman P, et al. From global health security to global health solidarity, security and sustainability. *Bull World Health Organ*. 2016;94(12):863.

Abbey Lowe, MA is a research ethics educator and doctoral student at the University of Nebraska Medical Center in Omaha. Her research interests are at the intersection of philosophy, health security, and bioethics.

Angela Hewlett, MD, MS is an associate professor of internal medicine and infectious diseases in the Department of Internal Medicine at the University of Nebraska Medical Center in Omaha, where she is also an associate professor in the College of Public Health. She is the medical director of the Nebraska Biocontainment Unit and participated in the care of several patients with Ebola virus disease in 2014. She has since provided subject matter expertise on biocontainment and the clinical management of patients with Ebola virus disease through the National Ebola Training and Education Center.

Toby Schonfeld, PhD, is the director of Prime Review Board, an independent institutional review board located in Rockville, Maryland. She is responsible for the oversight, maintenance, and improvement of Prime's Human Research Protection Program, including its institutional review board. She is a former

faculty member at Emory University and the University of Nebraska Medical Center, has worked in ethics at the US Environmental Protection Agency and the US Department of Veterans Affairs, and has produced more than 70 publications and 50 presentations.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2020;22(1):E16-21.

DOI

10.1001/amajethics.2020.16.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2020 American Medical Association. All rights reserved.
ISSN 2376-6980

MEDICAL EDUCATION

Five Things Students and Clinicians Should Know About "Biocontainment"

Helen Stanton Chapple, PhD, RN, MSN, MA

Abstract

Biocontaining was one way that Western, affluent, allopathic cultures tended to respond and make meaning during the 2013-2015 Ebola virus disease (EVD) pandemic. It became a pathway to restore trust in biomedicine itself, which had been shaken by unease across the globe when the EVD threat was at its height. Yet biocontaining barely qualifies as a public health measure. Successful public health efforts rely on trust, which is difficult to maintain during a pandemic. Such efforts require balancing the need to be close to patients to care well for them against the need to remain distant from a virulent pathogen. Biocontainment tries to navigate this tension and, in so doing, simultaneously frustrates and supports public trust. This article suggests 5 things clinicians and health professions students should consider about the project of biocontainment that could affect their orientation to their public health duties.

Contagion Control Relies on Trust

While I was composing this article in mid-2019, 2 viral contagions were making headlines: measles and Ebola virus disease (EVD).^{1,2} A reliable intervention to render the measles virus harmless once it enters the human body does not exist, while 2 new drugs for Ebola show promise.³ Without prevention, the only treatment for measles is hydration and supportive care. Absent the drugs still in trial, the same is true for EVD. Either can be fatal. Measles is the more contagious of the two because it is both airborne and passed by direct contact. Coughing or sneezing does not spread EVD, but direct contact with it is more likely to be fatal.⁴ A protective vaccine exists for each virus, but both of them can be impotent in the context of [public distrust](#). Bridling measles and EVD, especially as they can occur in combination, requires widespread conformity to public health advice and control measures, including vaccination.⁵

This article canvasses the role of biocontainment during the 2013-2015 outbreak of EVD in West Africa. Viewing biocontainment as part myth and part reality, this article shows how it is related to the most important priority in ethics for public health operations: establishing and maintaining trust.

Public Health's Dual Orientation

Public health is both a branch of medicine and an arm of government. As the former it is not as gripping as the drama of biomedicine can be. Ironically, the historical success of public health efforts in the United States (think clean water and improved nutrition) render it amorphous and less visible. As an arm of government, public health is meant to benefit citizens.⁶ But enacting regulations to promote public health requires funding in the short run, while long-term benefits can be difficult to measure. Those making policy decisions and allocating funds might not be the ones who benefit directly.⁷ The US orientation to individualized health care overshadows public health almost completely, until a crisis like a measles outbreak occurs. Perhaps public health's relative invisibility contributed to the surprising dazzle of biocontaining, an intervention that impressed the media with its exclusivity and expense and seemed to take public health to a whole new level.

Tantalizing New Response to Disease

During the EVD pandemic of 2013, the world saw a brand-new response to disease—biocontainment—demonstrated by a few resource-rich countries, notably the United States. Common forms of segregating persons known to be infected (such as isolation) or who might be infected to see if they manifest the disease ([quarantine](#)) paled in comparative appeal to the new shine of biocontainment. To biocontain was to render pristine a tiny section of a designated hospital—and then keep it that way—while inserting a dangerously infected patient into it. The emergence of biocontainment units and the publicity these units generated for their institutions and the enterprise of health care exhibited the full power of the biomedical project, as 3 resource-rich hospitals in the United States pulled out all the stops in terms of specialized staff, personal protective equipment, lab procedures, and waste management strategies displaying Western allopathic prowess in separating purity and contagion.⁸ In bald contrast were desperate public health efforts of resource-poor countries in West Africa to support EVD victims and contain disease. Ethically and clinically, the upshot here is that, although US biocontaining was highly publicized, it served only 9 patients, usually one at a time, of the thousands globally who contracted EVD.⁹

Biocontaining was and is part reality and part myth. Combining extreme methods of isolation, personal protective equipment (PPE), and waste disposal, biocontainment efforts proved that persons infected with EVD could, under its strict constraints, be treated safely and reliably. In the 2013-2015 EVD crisis, this reality became a pathway to restoring faith in biomedicine itself, which had been shaken by the unease that overspread the globe when EVD was at its height.⁹ Biocontaining marked the first attempt to treat humans contaminated with the virus as if they *were* the virus— by clinicians adopting the many protective barriers for patient care that lab workers typically require when working with the most dangerous pathogens.

Yet biocontaining barely qualifies as a public health measure, and, in this sense, it is a myth. In the Occupational Safety and Health Administration's hierarchy of controls, deploying PPE is the last resort, to be used only when 4 more effective interventions for virus containment have proven insufficient (elimination, substitution, engineering controls, and administrative controls).¹⁰

Biocontainment's inferior ranking is well deserved due to its lack of scalability, its expense (rendering it useless in resource-poor settings), its ineffectiveness compared to other public health measures, and its potential for alienation—on a personal level, due to the appearance and enforced distances necessitated by PPE, and on a public-perception level, due to the small number of patients who can actually be served by it.

A Rock Star of Public Health Is Born

All the same, in 2014, biocontaining was a rock star in the world of public health. Some of the fascination came from its origins in combatting bioterrorism, which had given public health a shot in the arm. The anthrax attacks of 2001 galvanized government agencies to prepare for biowarfare,⁷ and biocontainment units were born. Like biomedicine itself, biocontaining requires atomization and strives to isolate a singular object, emblematic of scientific research.¹¹ In comparison to the tidiness of scientific objectivity, routine public health seems messy, inexact, and unrefined. Yet it was the integration of public health protocols and community buy-in that, in the absence of a vaccine, finally halted EVD and saved countless lives during the 2013-2015 outbreak.¹²

Need for Trust in Public Health

The Centers for Disease Control and Prevention counts new vaccines for vaccine-preventable diseases as among the most effective public health interventions of the 20th century.¹³ **Resistance to vaccination** is a factor in both measles and EVD outbreaks.^{14,15} It is my purpose here not to reiterate the science and merits of vaccination but rather to call attention to a deeper issue central to vaccination's success.

When a disease outbreak occurs, something far more mundane and complex than biocontaining and even vaccination must take center stage: establishing and maintaining trust in order to support humans and their relationships. Leaders of pluralistic societies typically struggle to define who is "us" and who is "other," as do those they represent. In the face of public contagion and fear of contamination, tension between *us* and *other* is starkly visible, and line-drawing has high ethical, social, and cultural stakes. We want to protect ourselves and our loved ones from danger. But the sick and the potentially sick are both *us* and *other*—simultaneously dearly loved and highly dangerous. This tension is heartbreakingly evident in cases of a hemorrhagic fever like EVD, in which suffering is so evident and the need to be close to deliver care or prepare for burial is both compelling and menacing. What role does and should trust play in balancing our need to be close and our need—in accord with public health measures of disease containment—to be distant?

Childress et al describe 9 "general moral considerations" in public health, among them respecting autonomy, fidelity, and minimizing intrusion.⁶ Trust, though listed last, is foundational to the other eight. Without confident relationships among policymakers, clinicians, and members of the public, public health efforts such as vaccination are doomed to failure. Accordingly, clinicians and health professions students should implement 5 lessons from the phenomenon of biocontaining when they are responding to or planning

for a pandemic, because in doing so they might be better able to connect public health duties to social relationships and thereby cement trust.

5 Lessons From Biocontaining

In view of 2019's active threats of contagion, it makes sense to ask, *What are the top 5 things clinicians and health professions students should consider about biocontaining that could affect how they orient themselves to their public health duties?* This question is critical if biocontaining cannot, due to its infrastructure demands and cost, be a safety net in a pandemic, despite its evident appeal.

1. *Violence, tribalism, and stigma disrupt and destabilize society.* These factors complicate public health efforts because they enfeeble trust. Clinicians must avoid "othering" either victims or nonconformists (such as those who resist vaccination) in personal reflection and in communication. Pandemic-related efforts must ensure social and financial support for those separated for observation or quarantine.¹⁶
2. *Narrative medicine is a model.* Charon encourages consideration of the multilayered context between physician and patient¹⁶; public health workers must attend carefully to context as well. As particular localities and constituencies involve themselves in pandemic response, the stakes and the networking challenges for outside responders mushroom. Collaborative authority¹⁷ can be achieved by inviting and welcoming community members' input and fully incorporating it in decision making.¹⁸ The goal is a public health effort that "expresses community"⁶ rather than imposes naked governmental authority.
3. *Disbelief in the public health messages comes from lack of faith in the messenger, especially if she or he is "other."* In the Democratic Republic of the Congo, the public health response to EVD is occurring amidst social upheaval, and rumors fly that Ebola itself is a fabrication.¹⁵ Vaccination cannot save people when a threat seems ephemeral or "cooked up." Trust is necessary for both the message to express community and the messenger to build collaborative authority.¹⁹ Public messaging can raise awareness while reducing stigma and avoiding blame.
4. *Demonstrating fairness is a priority for trust.* How can clinicians work to close the gap between resource-rich and resource-poor environments when treating EVD? Tapping into community knowledge and leadership can demonstrate collaborative authority to address this requirement locally. Yet, as the world shrinks, outbreaks anywhere on the globe affect both *us* and *other*. Enlightened self-interest can motivate striving for and achieving equity in distributing public health containment measures.
5. *Biocontaining simultaneously supports and frustrates public trust.* Biocontaining is trustworthy in terms of its effectiveness as a last resort. But it is also inequitable in terms of its accessibility, thereby

subverting trust. The required investment in physical resources, setting, training, and staff to implement it fully is out of reach for most health care delivery systems in the world. Hospitals with biocontainment facilities can admit only miniscule numbers of patients. Favoring so few with specialized, sought-after care during a pandemic will challenge public health triage methods unimaginably.

References

1. Bortor G. US records 33 new measles cases, mostly in New York State. *Reuters*. June 24, 2019. <https://www.reuters.com/article/us-usa-measles/us-records-33-new-measles-cases-mostly-in-new-york-state-idUSKCN1TP1RB>. Accessed July 10, 2019.
2. Hayden S. How misinformation is making it almost impossible to contain the Ebola outbreak in DRC. *Time*. June 20, 2019. <https://time.com/5609718/rumors-spread-ebola-drc/>. Accessed on July 10, 2019.
3. World Health Organization. Update on Ebola drug trial: two strong performers identified. <https://www.who.int/news-room/detail/12-08-2019-update-on-ebola-drug-trial-two-strong-performers-identified>. Published August 12, 2019. Accessed October 1, 2019.
4. Kaiser Family Foundation. Ebola: five key questions. <https://www.kff.org/infographic/ebola-characteristics-and-comparisons-to-other-infectious-diseases/>. Published May 14, 2018. Accessed October 1, 2019.
5. Mole B. Measles is killing more people in the DRC than Ebola—and faster. *Ars Technica*. July 15, 2019. <https://arstechnica.com/science/2019/07/measles-is-killing-more-people-in-the-drc-than-ebola-and-faster/>. Accessed October 1, 2019.
6. Childress JF, Faden RR, Gaare RD, et al. Public health ethics: mapping the terrain. *J Law Med Ethics*. 2002;30(2):170-178.
7. Schneider MJ. *Introduction to Public Health*. 5th ed. Burlington, MA: Jones & Bartlett Learning; 2017.
8. Douglas M. *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo*. New York, NY: Routledge; 1966.
9. Chapple HS, Schenck D. Biocontaining: purification, restoration, and meaning-making. *Perspect Biol Med*. 2017;60(2):166-185.
10. National Institute for Occupational Safety and Health (NIOSH), Centers for Disease Control and Prevention. Hierarchy of controls. <https://www.cdc.gov/niosh/topics/hierarchy/default.html>. Reviewed January 13, 2015. Accessed August 26, 2019.
11. Gordon D. Tenacious assumptions in Western medicine. In Locke M, Gordon D, eds. *Biomedicine Examined*. Dordrecht, The Netherlands: Kluwer Academic Publishers; 1988:19-56.
12. World Health Organization. What needs to happen in 2015. <https://www.who.int/csr/disease/ebola/one-year-report/response-in-2015/en/>. Published January 2015. Accessed October 2, 2019.
13. Ten great public health achievements—United States, 2001-2010. *MMWR Morb Mortal Wkly Rep (MMWR)*. 2011;60(19):619-623.

14. Infectious Diseases Society of America. Measles vaccination: myths and facts. <https://www.idsociety.org/public-health/measles/myths-and-facts/>. Accessed October 2, 2019.
15. Vinck P, Pham PN, Bindu KK, Bedford J, Niles EJ. Institutional trust and misinformation in the response to the 2018-19 Ebola outbreak in North Kivu, DR Congo: a population-based survey. *Lancet Infect Dis*. 2019;19(5):529-536.
16. Merkel H, Gostin LO, Fidler DP. Extensively drug-resistant tuberculosis: an isolation order, public health powers, and a global crisis. *JAMA*. 2007;298(1):83-86.
17. Charon R. Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA*. 2001;286(15):1897-1901.
18. Nembhard IM, Edmondson AC. Making it safe: the effects of leader inclusiveness on psychological safety and improvement efforts in healthcare teams. *J Organ Behav*. 2006;27(7):941-966.
19. Centers for Disease Control and Prevention. *Dikembe Mutombo Ebola PSA* [video]. <https://www.cdc.gov/vhf/ebola/outbreaks/drc/Dikembe-Mutombo-Ebola-PSA.html>. Reviewed June 20, 2019. Accessed October 2, 2019.

Helen Stanton Chapple, PhD, RN, MSN, MA, is a professor at Creighton University in Omaha, Nebraska, where she teaches in the Master of Health Care Ethics program. Her twenty years of bedside nursing include oncology, research, hospice home care, and cardiac and neuroscience critical care.

Citation

AMA J Ethics. 2020;22(1):E22-27.

DOI

10.1001/amajethics.2020.22.

Acknowledgements

The author would like to acknowledge Jason Wilken, PhD, of the Centers for Disease Control and Prevention, for offering his expertise on this topic in a private communication.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2020 American Medical Association. All rights reserved.
ISSN 2376-6980

IN THE LITERATURE

How Should the WHO Guide Access and Benefit Sharing During Infectious Disease Outbreaks?

Nicholas G. Evans, PhD, Kelly Hills, and Adam C. Levine, MD

Abstract

In response to the 2013-2016 Ebola virus disease (EVD) outbreak primarily affecting Guinea, Sierra Leone, and Liberia, the World Health Organization (WHO) set out *Guidance for Managing Ethical Issues in Infectious Disease Outbreaks*, which covered social distancing, research in outbreak settings, and clinical care. This article assesses the *Guidance's* recommendations on research and long-term storage of biological specimens during infectious disease outbreaks and argues that the *Guidance* does not provide adequate direction for responders', researchers', and organizations' actions. It considers local persons' access to benefits of research in the aftermath of outbreaks and preparedness for outbreaks, drawing on lessons from both the 2013-2016 EVD outbreak and ongoing research in the Democratic Republic of the Congo.

Introduction

In 2016, the World Health Organization (WHO) published *Guidance for Managing Ethical Issues in Infectious Disease Outbreaks*.¹ The *Guidance* arose in the context of the 2013-2016 Ebola virus disease (EVD) outbreak that primarily affected the Western African nations of Liberia, Sierra Leone, and Guinea; cases also arose in 7 other nations.² That outbreak, declared a public health emergency of international concern (PHEIC) in August 2014,³ resulted in more than 28 000 suspected cases and 11 325 confirmed deaths.²

The WHO guidelines are particularly salient in light of the current EVD outbreak in the North Kivu and Ituri provinces of the Democratic Republic of the Congo (DRC), declared a PHEIC in July 2019.⁴ They span the gamut of bioethical issues: public engagement, allocation of scarce resources, public health surveillance, duty to treat, clinical research, use of experimental interventions, and vulnerability in the context of international and domestic sources of structural inequality.¹ Many, if not most, of these concerns are not new and have been raised in the context of human immunodeficiency virus (HIV),⁵ armed conflicts,^{6,7} and previous EVD outbreaks.⁸ Nonetheless, the document is important for its scope and particular focus on infectious disease outbreaks within the purview of the *International Health Regulations* (IHR), from which PHEIC declarations arise.⁹

Infectious disease outbreaks are, in cases like EVD, one of the only times scientists can study a disease *in situ*. Clinical data on EVD is generally only collected in the context of outbreak responses.¹⁰ Moreover, testing novel vaccines and interventions on humans is sometimes only possible in the context

of outbreaks, especially when it would be too risky to pursue human challenge experiments (ie, intentionally infecting subjects).¹¹ Subjects of scientific¹² and therapeutic research have some [claim to benefits](#) that arise from knowledge generated through their involvement in science and medicine, as may the communities in which those subjects reside. What that claim entails and how it should be executed, however, is subject to debate.

The management of EVD continues to raise serious questions about what the obligation to share scientific and clinical benefits entails, how to discharge that obligation, and who ought to discharge it. In March 2019, it was reported that blood samples taken during the West African EVD outbreak, which were reportedly held by American and British authorities, were being withheld from researchers in the countries they were taken from.¹³ Among other values, security was used to justify limiting access, as Ebola virus is considered a pathogen with high potential for development into a biological weapon. In June 2019, reporting from the DRC detailed ongoing negotiations to make vaccines tested in Western Africa affordable for widespread use, a process that was in limbo because of policies not to disclose the price of development and manufacture of the vaccine.¹⁴ The same report noted that of the thousands of samples collected by predominantly Western responders from patients in Liberia, Guinea, and Sierra Leone, neither the samples nor the proceeds from their sale and use in research had made their way back to their respective countries of origin. This circumstance was attributed, among other reasons, to the United States' decision to not sign the Nagoya Protocol to the Convention on Biological Diversity,^{15,16} which would require mutually agreed-upon terms when exporting genetic samples from signatory countries (though, as some have argued, the ratification of the protocol by the host country alone may be sufficient to enforce this requirement¹⁵). As discussed below, the *Guidance* provides a broad framework for articulating what nations, including the United States, ought to do regarding benefit sharing during infectious disease outbreaks, but understanding why they ought to do it requires further interpretation, which we provide here.

Sharing Benefits of Research

Infectious disease outbreaks produce at least 3 broad classes of tangible objects or data that benefit individuals and communities. First, the treatment of patients produces clinical data that is useful in understanding the pathophysiology of disease, improving diagnosis and management, and improving public health surveillance. Second, collection of samples provides sequence data for humans and viruses, which are useful in the development of surveillance technologies, diagnostics, and medical interventions. Finally, the use of experimental interventions in outbreaks provides information and tangible products such as vaccines and therapeutics.^{1,17}

The WHO claims all three of the above benefits should be shared.¹ Section 10 of the *Guidance* states that clinical data must be shared rapidly to assist in responding to an outbreak. It notes that "every researcher who engages in generation of information related to a public health emergency or acute public health event with the potential to progress to an emergency has the fundamental moral obligation to share preliminary results once they are adequately quality controlled for release."¹ Regarding samples, the *Guidance* requires individuals and organizations involved in the long-term storage of samples to engage communities in dialogue about the conditions of storing, transferring, and sharing of those specimens for future use. Finally, the WHO

states that existing international guidelines on research ethics mandate that individuals and communities participating in research should have access to any benefits that result from their participation. These points of guidance, however, are inadequate in the absence of a more thoroughgoing analysis of the ethical basis for benefit sharing.

The Moral Justification for Benefit Sharing

To begin, it might be asked why individuals and their communities ought to receive access to the benefits of science and medicine. A skeptic might argue that participants in research frequently give informed consent knowing that benefits may never arise.¹⁸ If participants or others enter freely into a contract with a researcher with no promise of access to benefits even if they do arise, a skeptic might then argue that there is no reason to believe this is an invalid form of contract.

We identify 4 major reasons—utility, equity, justice, and liberty—why benefit sharing is necessary and why researchers, institutions, companies, and governments are obliged to offer specific people and communities access to the benefits arising from some kinds of research. These reasons need not all apply to the same kinds of benefits, recipients, or providers; any one may suffice.^{19,20} These reasons, we argue further, are particularly salient in infectious disease outbreaks with implications for global health security—which often arise in resource-deprived communities that might be current or former victims of armed conflict or colonization—especially when such outbreaks occur in low- and middle-income countries.

Utility. Early intervention in an outbreak is better than a delayed response when an epidemic has had a chance to spread widely. Put in explicitly ethical terms, the utility of an intervention—its capacity to promote community or global well-being—is, all other things being equal, likely to be much higher the sooner we act. In the context of research on EVD, the utility of research and medicine is greatly diminished if countries and communities initially and directly affected by outbreaks are unable to access lifesaving interventions or data that would enable care. Insofar as we have an obligation to ensure that medical research promotes its stated benefits—in this case, preventing an EVD epidemic—we ought to make the results of research available.

Equity. The WHO defines inequities as “inequalities that are judged to be unfair, that is, both unacceptable and avoidable,” and notes that equity must be reached between countries.²¹ While some might argue that sharing the benefits of biomedical research can be very costly, it can be justified if it promotes equity. For example, blood samples from patients with EVD from Western African countries have been found to be very lucrative for their potential use in research and drug development, with one report indicating samples may fetch more than €3600 per 0.5 mL.¹⁴ Under principles of fair allocation of resources or equity, countries whose citizens have provided samples ought to have access to those samples, even if this access were to diminish the financial benefit organizations gain by selling those samples on the open market. This is not to say that, should resources be available, such samples ought not to be sold, only that samples first be shared with the appropriate researchers and countries. As with other areas of genetics and genomics, the potential for great innovation—or financial gain—is not sufficient to justify inequity in socially and economically disadvantaged groups who have been further harmed by an epidemic in their community.²¹

Justice. The nations that have most recently experienced EVD outbreaks have been subject to a legacy of colonialism, forced resource extraction, and exploitation by developed nations. The benefit produced for the West cannot be understated; for example, the United States of America received roughly 80% of the uranium ore that would form the core of the nuclear weapons created in the Manhattan Project from the Belgian-controlled Congo, at the cost of lives and resources from the land and people now known as the DRC.²³ Contemporarily, the tantalum used in cellphones (among other electronics) is extracted from mines in the DRC, often under forced labor and slave-like conditions.²⁴ Economic inequalities and corresponding health inequalities in the DRC are often rooted in historical and ongoing injustices perpetuated or strategically tolerated by developed nations. In this case, taking samples and clinical knowledge from bodies of sick patients in the DRC without commensurate benefits to those patients and their communities perpetuates and mirrors the historical injustice of resource extraction from DRC land and exploitation of bodies in the DRC.

A central demand of [global health justice](#) is to seek to *repair* people who have been victims of injustice.²⁵ It is incumbent on developed nations to make available data, samples, and interventions as part of an effort to redress historical health, social, and economic injustices.

Liberty. Theories of contract typically presume a scheme of just initial acquisitions: we all start off with a fair amount of goods with which to trade.²⁶ Under such a system, the skeptical argument as presented above would be justifiable as long as individuals made the informed choice to enter into scientific research (or medical care) with no expectation of return. Yet this is not the case due to the history of the region: the DRC's health care system is underresourced; the nation is embroiled in civil conflict; and the country lacks a rival pharmaceutical industry on the scale of North America's or Europe's, in part because the resources of the developed world are built on theft and [exploitation](#). As such, it is unlikely any individual contract can be meaningfully free and informed.

There is therefore an obligation to ensure redress so that vulnerable populations can negotiate contracts on fair terms, keeping in mind that leaving a people with *only* their bodies (including their blood) as resources to be sold seems to violate Article 4 of the United Nations Universal Declaration on Human Rights. ("No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms".²⁷) Benefit sharing during infectious disease outbreaks thus could form part of the transfers that count towards redressing these initial thefts. Other transfers would include capacity building in terms of local infrastructure and scientific resources.

Challenges to Benefit Sharing

Despite strong reasons to engage in benefit sharing, practical hurdles remain that the *Guidance* does not address. [Sharing clinical data](#), for example, requires collecting sufficient amounts of it—and in the right formats—to be meaningful and providing a platform on which it can be accessed.²⁸ These data might be the property of a variety of different actors and therefore subject to different kinds of ownership and legal regime.²⁹ Moreover, securing consent to share clinical data collected from patients who were unable to give consent at the time of treatment may be difficult or impossible, given the potential of patients and next

of kin to be displaced by outbreaks. However, we note that as these samples continue to be used and shared after the outbreak, investigators and their institutions might need to spend time and resources to secure consent for future work.

Samples pose different challenges. Samples can be costly to store, requiring expensive freezers and generators to maintain a continuous cold chain (ie, a refrigerated supply chain for medical supplies). Even with the capacity to store samples, laboratories in low- and middle-income countries may lack the appropriate molecular diagnostics to work with those samples. For some emerging infectious diseases that pose a serious safety or security threat, such as EVD, there may also be challenges in ensuring samples are stored in a way that secures them against theft or misuse—even inadvertently, such as occurred when a taxi functioning as a courier for samples was robbed in Guinea in 2014, with the bandits inadvertently making off with infected blood samples.³⁰ While it might seem easiest and most efficient to ship samples to high-income countries that already have capacity for safe storage and handling, the aforementioned demands of justice and equity argue instead for establishing appropriate infrastructure within affected countries. One reason given for the taxi robbery in Guinea in 2014, for example, was that the Guinea Red Cross lacked its own vehicles in which to securely transport blood samples.³¹ Developing local infrastructure has the additional benefit of creating research, detection, and prevention facilities, which are of obvious utility and promote liberty.

A central question regarding the sharing of tangible products such as therapeutics or vaccines is cost. It is not sufficient to claim these products should be shared: a mechanism to pay for and distribute them needs to be found. In some cases, charitable donations or nongovernmental organizations such as Gavi, the Vaccine Alliance can serve this function. In others, it may be governments or drug companies that provide therapeutics or vaccines at reduced or no cost to those who need them—as did Merck, the manufacturers of the rVSV-ZEBOV Ebola vaccine, working with the US Department of Health and Human Services.³² Nevertheless, cost is not simply a matter of the cost of producing a vaccine or therapeutic procedure. Benefit sharing may also require necessary infrastructure, such as cold chains to store and deploy products once shared, research facilities and laboratories, or basic utility systems and roadworks.

In general, overcoming these infrastructural and other considerations requires addressing them early, ideally ahead of an outbreak. In the case of clinical data collection, developing accessible, standard platforms for data can be done well ahead of any emergency. In the case of vaccines and therapeutics, better national implementation of—and support for—the *International Health Regulations*³³ can provide a basis for sharing that is equitable and negotiated ahead of time. And investment in nations' health care infrastructure, including laboratories, and physical infrastructure (roads, water, power) before epidemics emerge can prevent outbreaks from becoming health emergencies.

Conclusion

The ongoing EVD outbreak in the DRC remains out of control. There are a range of challenges in resolving the epidemic, but one of them is securing access to the products of previous outbreaks to benefit those currently affected by the disease. The *Guidance* provides a principled basis for such access as well as for

sharing benefits that will arise from the current outbreak in the DRC with those affected in order to better prepare for future Ebola virus disease outbreaks—which, given the past history of outbreaks in the region, we can assume with confidence will happen again.⁹ The underlying ethical principles of utility, equity, justice, and liberty are broad and subject to practical concerns, but they provide a roadmap for delivering the benefits of the life sciences to affected peoples.

References

1. World Health Organization. *Guidance for Managing Ethical Issues in Infectious Disease Outbreaks*. Geneva, Switzerland: World Health Organization; 2016.
<https://apps.who.int/iris/bitstream/handle/10665/250580/9789241549837-eng.pdf>. Accessed October 3, 2019.
2. Centers for Disease Control and Prevention. 2014–2016 Ebola outbreak in West Africa. <https://www.cdc.gov/vhf/ebola/history/2014-2016-outbreak/index.html>. Reviewed March 8, 2019. Accessed on September 12, 2019.
3. World Health Organization. Statement on the 1st meeting of the IHR Emergency Committee on the 2014 Ebola outbreak in West Africa. <https://www.who.int/mediacentre/news/statements/2014/ebola-20140808/en/>. Published August 8, 2014. Accessed on July 29, 2019.
4. Ebola outbreak in the Democratic Republic of the Congo declared a public health emergency of international concern [press release]. Geneva, Switzerland: World Health Organization; July 17, 2019.
<https://www.who.int/news-room/detail/17-07-2019-ebola-outbreak-in-the-democratic-republic-of-the-congo-declared-a-public-health-emergency-of-international-concern>. Accessed September 4, 2019.
5. Evans NG. Balancing the duty to treat patients with Ebola virus disease with the risks to dialysis personnel. *Clin J Am Soc Nephrol*. 2015;10(12):2263–2267.
6. Gross M. *Bioethics and Armed Conflict*. Cambridge, MA: MIT Press; 2006.
7. Evans NG, Sekkarie MA. Allocating scarce medical resources during armed conflict: ethical issues. *Disaster Mil Med*. 2017;3(1):5.
8. Hewlett BL, Hewlett BS. Providing care and facing death: nursing during Ebola outbreaks in Central Africa. *J Transcult Nurs*. 2005;16(4):289–297.
9. World Health Organization. *International Health Regulations*. 3rd ed. Geneva, Switzerland: World Health Organization; 2005.
<https://apps.who.int/iris/rest/bitstreams/1031116/retrieve>. Accessed November 13, 2019.
10. Henwood PC. Ebola in West Africa: from the *Frontline*. In: Evans NG, Smith TC, Majumder MS, eds. *Ebola's Message: Public Health and Medicine in the Twenty-First Century*. Cambridge, MA: MIT Press; 2016:15–30.
11. Miller FG, Grady C. The ethical challenge of infection-inducing challenge experiments. *Clin Infect Dis*. 2001;33(7):1028–1033.
12. Evans NG, Lipsitch M, Levinson M. The ethics of biosafety considerations in gain-of-function research resulting in the creation of potential pandemic pathogens. *J Med Ethics*. 2015;41(11):901–908.
13. McKenna M. Colonialists are coming for blood—literally. *Wired*. March 3, 2019. <https://www.wired.com/story/ebola-epidemic-blood-samples/>. Accessed June 12, 2019.
14. Freudenthal E. A short history of an Ebola vaccine. *New Humanitarian*. June 4, 2019.

<http://www.thenewhumanitarian.org/analysis/2019/06/04/short-history-ebola-vaccine>. Accessed June 12, 2019.

15. McCluskey K, Barker KB, Barton HA, et al. The US Culture Collection Network responding to the requirements of the Nagoya Protocol on access and benefit sharing. *MBio*. 2017;8(4):e00982-17.
16. Convention on Biological Diversity, United Nations. Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising From Their Utilization to the Convention on Biological Diversity. <https://www.cbd.int/abs/doc/protocol/nagoya-protocol-en.pdf>. Published 2011. Accessed October 4, 2019.
17. Evans NG, Inglesby T. Biosecurity and public health ethics issues raised by biological threats. In: Mastroianni AC, Kahn JP, and Kass NE, eds. *The Oxford Handbook of Public Health Ethics*. Oxford, UK: Oxford University Press; 2019:774-785.
18. Truog RD, Kesselheim AS, Joffe S. Paying patients for their tissue: the legacy of Henrietta Lacks. *Science*. 2012;337(6090):37-38.
19. Selgelid MJ. A moderate pluralist approach to public health policy and ethics. *Public Health Ethics*. 2009;2(2):195-205.
20. Buchanan AE. The right to a decent minimum of health care. *Philos Public Aff*. 1984;13(1):55-78.
21. World Health Organization. Equity. <https://www.who.int/gender-equity-rights/understanding/equity-definition/en/>. Accessed October 3, 2019.
22. Samuel GN, Selgelid MJ, Kerridge I. Managing the unimaginable. Regulatory responses to the challenges posed by synthetic biology and synthetic genomics. *EMBO Rep*. 2009;10(1):7-11.
23. Fleckner M, Avery J. Congo uranium and the tragedy of Hiroshima. Paper presented at: 55th Pugwash Conference; July 22-27, 2005; Hiroshima, Japan. <http://s2.e-monsite.com/2010/05/31/82250333congo-uranium-pdf.pdf>. Accessed September 7, 2019.
24. Graff J. Corporate war criminals and the international criminal court: blood and profits in the Democratic Republic of Congo. *Human Rights Brief*. 2004;11(2):23-26.
25. Farmer P. *Pathologies of Power*. Berkeley, CA: University of California Press; 2004.
26. Nozick R. *Anarchy, State, and Utopia*. New York, NY: Basis Books; 1974.
27. United Nations. Universal Declaration of Human Rights. https://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf. Accessed September 7, 2019.
28. Roshania R, Mallow M, Dunbar N, et al. Successful implementation of a multicountry clinical surveillance and data collection system for Ebola virus disease in West Africa: findings and lessons learned. *Glob Health Sci Pract*. 2016;4(3):394-409.
29. Levine AC. Academics are from Mars, humanitarians are from Venus: finding common ground to improve research during humanitarian emergencies. *Clin Trials*. 2016;13(1):79-82.
30. Coltart C, Lindsey B, Ghinai I, Johnson A, Heymann D. The Ebola outbreak, 2013-2016: old lessons for new epidemics. *Philos Trans R Soc Lond B Biol Sci*. 2017;372(1721):20160297.
31. Associated Press in Conarky. Bandits in Guinea steal blood samples believed to be infected with Ebola. *Guardian*. November 21, 2014. <https://www.theguardian.com/world/2014/nov/21/bandits-guinea-steal-blood-samples-possibly-infected-with-ebola>. Accessed September 11, 2019.

32. HHS funds an additional year of Ebola vaccine manufacturing [press release]. Washington, DC: US Department of Health and Human Services. August 21, 2019. <https://www.hhs.gov/about/news/2019/08/21/hhs-funds-an-additional-year-of-ebola-vaccine-manufacturing.html>. Accessed September 7, 2019.

Nicholas G. Evans, PhD is an assistant professor in the Department of Philosophy at the University of Massachusetts Lowell, where he works on issues related to biosecurity and emerging infectious diseases. He is the co-editor of *Ebola's Message: Public Health and Medicine in the Twenty-First Century* (MIT Press, 2016).

Kelly Hills is a founding bioethicist of the consulting firm Rogue Bioethics. Her current research projects include international bioethics, biosafety, science communication norms, and ethical issues concerning novel technologies, such as synthetic biology and genome editing.

Adam C. Levine, MD is an associate professor of emergency medicine and the director of the Division of Global Emergency Medicine at the Warren Alpert Medical School at Brown University in Providence, Rhode Island, where he is also the director of the Center for Human Rights and Humanitarian Studies at the Watson Institute for International and Public Affairs. In addition, he serves as the primary investigator for the Global Emergency Response and Recovery Partner Engagement Cooperative Agreement between the International Medical Corps and Centers for Disease Control and Prevention. His research focuses on improving the delivery of emergency care in resource-limited settings and during humanitarian emergencies

Editor's Note

Background image by John Lambert.

Citation

AMA J Ethics. 2020;22(1):E28-35.

DOI

10.1001/amajethics.2020.28.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2020 American Medical Association. All rights reserved.
ISSN 2376-6980

HEALTH LAW

When Are Vaccine Mandates Appropriate?

Carmel Shachar, JD, MPH and Dorit Rubinstein Reiss, LLB, PhD

Abstract

Vaccine refusal is a serious public health problem, especially in the context of diseases with potential to spark global pandemics, such as Ebola virus disease in the Democratic Republic of the Congo. This article examines whether and when compelling vaccination through mandates and criminalization, for example, are appropriate. It argues that some legal approaches are ethical when they preserve social stability, trust in government, therapeutic research opportunities, or when they diminish disease severity.

Introduction

Nowhere is Ebola virus disease (EVD) a more serious global public health concern than in the Democratic Republic of the Congo (DRC), where the world's second largest outbreak resulted in 3200 cases and 2100 deaths from August 1, 2018 through September 24, 2019.¹ Fortunately, experimental Ebola vaccines have been rapidly developed and are being tested,² and many hope that they will be useful in time to help respond to the most recent outbreak. According to data released by the World Health Organization (WHO), one of the vaccines is 97.5% effective.³ Among more than 90 000 vaccinated individuals, only 71 developed Ebola, with only 15 developing the disease more than 10 days after vaccination when vaccines are assumed to be fully protective, while the remaining 56 developed EVD during the initial 10 day period in which the vaccine is thought to confer only partial protection at best.³ The new Ebola vaccine represents an important opportunity to combat a potentially pandemic disease.

Vaccines, however, are only effective when enough people receive them within a given population. Due to serious repression and human rights violations,⁴ the Congolese might be rightfully wary of coercive measures taken by their government, no matter how well intentioned. Another challenge to vaccine uptake is that, in the DRC, people in EVD outbreak regions also face military and paramilitary violence and political turmoil. The cities of Katwa and Butembo, for example, are too dangerous for WHO personnel to visit to administer vaccines.⁵ Attacks on Ebola treatment centers in both cities⁵ demonstrate not only perpetrators' violence but also their distrust of international health interventions and Ebola vaccine campaigns. Although no attacks have been reported in South Kivu province, where another outbreak has occurred,⁶ it is possible that they will spread. This article examines whether and when legal approaches to Ebola vaccine refusal and reluctance, such as mandates and criminalization, are appropriate.

Legal Frameworks for Vaccination

Legal approaches to increasing vaccination rates range from the most coercive—actual physical force, eg, police coming to people's houses to forcefully vaccinate them—to least coercive, eg, educational modules.⁷ Because the United States considers public health to be largely governed by states, it has a diverse and robust set of legal standards concerning this issue that provide a range of options to draw on; we therefore can learn from the US legal framework. Vaccine mandates, when backed by criminal sanctions (rare in the United States⁷) or by limiting access to schools, services, and jobs are on the coercive side of this continuum, although they are not as coercive as physical force. Mandates can also differ with respect to populations to which they apply, such as children, professionals, or adults; in strength of penalties levied when violated; in rigor of enforcement; and in the nature and scope of exemptions they allow. Exemptions are generally allowed—appropriately—for persons with health conditions that might be exacerbated by vaccine administration. For example, although all US states have vaccine requirements for [children attending school](#), they all also have medical exemptions.⁸

Governments, even liberal democratic ones, limit individuals' autonomy, and one question is whether and when restrictions are justified. In 1905, in *Jacobson v Massachusetts*,⁹ the US Supreme Court concluded that states may require vaccination via mandate accompanied by a criminal fine, as long as the mandate is reasonable. The Court explained:

[T]he liberty secured by the Constitution of the United States to every person within its jurisdiction does not import an absolute right in each person to be, at all times and in all circumstances, wholly freed from restraint. There are manifold restraints to which every person is necessarily subject for the common good. On any other basis, organized society could not exist with safety to its members.⁹

Since *Jacobson*, the value courts and society place on individual bodily autonomy has increased, and autonomy has even been raised to the level of a fundamental right. US adults today have a right to decline even life-saving treatment, for example.¹⁰ Extrapolating this right to the DRC, we would permit DRC citizens to refuse an Ebola vaccination even though it might save lives. However, it is also recognized that the state can act to protect persons other than the affected person, even at the cost of limiting fundamental individual liberties. For example, the state's power to limit individual freedom to protect communities is exercised when quarantining or isolating—even by force—individuals who pose risk (of infection, perhaps) to others; the legitimacy of this exercise of state power is settled legal doctrine.¹¹ Not vaccinating also has implications beyond an individual, and the state can step in to regulate vaccine administration under this same authority. In the right circumstances, this authority justifies vaccine mandates with criminal sanctions or by limiting mandate violators' access to schools, services, and jobs.⁷ In the DRC context, we might reject an objector's [refusal of vaccination](#) on the basis that refusing places not only his or her life at risk, but also the lives of other members of the community, especially considering the highly infectious nature of EVD.

The state's authority to impose mandates with consequences is even more extensive when applied to children, who are not legally regarded as autonomous, as adults are.⁷ The United States is one of many countries with a long history of using school mandates to increase vaccination rates^{7,12}; these mandates have been consistently upheld by US courts against claims that they violate individual rights.¹³ Although all states provide medical exemptions,⁸ they vary in nonmedical (eg, religious or personal belief) exemptions. Adults who violate these mandates may not be able to send their child to school.⁸ Internationally, Italy and France impose fines on parents who do not vaccinate their children¹²; in France, jail time (though we are unaware of any cases of parents actually jailed) is a potential consequence of vaccine mandate violation.¹⁴

States are understandably more reluctant to mandate experimental vaccines, such as the current Ebola vaccines, but there is some precedent for widespread administration of novel vaccines when the public health threat is significant enough. In 1954, for example, 623 972 US children were injected with the then-experimental polio vaccine or a placebo and more than a million other children received the vaccine in an observed control design at the direction of state public health officials.¹⁵

Ethical Justification of Legal Approaches

Because no society protects individual freedom to an absolute degree, when is it ethical and reasonable to limit individual freedom? The following criteria are used by the courts to assess the reasonableness of limits on individual freedom: (1) proportionality, (2) precedent, (3) context, and (4) sufficiency of access to the good or service being mandated. Here, we apply these criteria to limits on individual freedom with regard to vaccination.

1. *Proportionality.* Higher levels of risk justify more restrictive limitations on individual freedom, where risk is construed as a combination of risks posed by a disease and the ease of transmission of that disease in relevant local circumstances.
2. *Precedent.* Precedent set by prior limitations on individual freedom matters: more coercive or restrictive approaches should generally only follow failures of less coercive or restrictive approaches. That is, unless there is an immediate, severe risk, adults should be free to exercise their autonomy to the extent that vaccination rates afford sufficient public protection.
3. *Context.* Social and cultural context of liberty restrictions must also be considered. In areas where government is unstable or in societies in which trust is fragile, coercive measures could undermine what's left of a state's stability or a society's trust. Liberty restriction and coercion can exacerbate distrust, suggesting the appeal of less restrictive and less coercive **education-based approaches**. Two drawbacks of education-based approaches, however, are that they might not be trusted by some or might not be sufficiently protective of public safety.

4. *Sufficiency of access.* Restrictive, coercive legal approaches require sufficient access to the good or service being mandated. That is, it is patently unfair and nonsensical to demand compliance with vaccination policies without making vaccines sufficiently available to those subject to a mandate. This reasoning suggests the importance of the state's capacity to provide adequate supply for the vaccine for which a mandate creates demand.

Implementing Mandates

Assuming a vaccine mandate is justifiable according to the 4 criteria just described, when and how should a vaccine mandate be enforced? It's worth noting that vaccine mandates tend to fail when they do not or cannot account for plurality among perceptions, values, and beliefs that drive individuals' vaccination choices. In the United States, for example, ignoring a legacy of maltreatment of African-Americans by the medical establishment (eg, the US Public Health Service Syphilis Study at Tuskegee^{16,17}) can undermine understanding of why some African-American parents might not be motivated to comply with a government mandate to vaccinate their children. Opponents of vaccination can be categorized in a variety of ways—for example, as religious objectors, political libertarians, and self-interest maximizers—that help explain how mandates affect vaccination choices.¹⁸ A religious objector might require a mandate with a harsh penalty in order to comply with a mandate, while that same penalty could strengthen a political libertarian's reluctance to vaccinate. Before implementing a broad vaccine mandate in the DRC, then, public health officials would be wise to consider the most common reasons for vaccine refusal and work to address those concerns. This precaution is especially relevant considering the experimental nature of the current vaccines, which could arouse concerns that vaccine acceptance is tantamount to agreeing to participate in experimentation.

Paradoxically, in some contexts, a vaccine mandate could undermine public confidence in the vaccine, resulting in fewer people being vaccinated. For example, in 1853, England passed the National Vaccination Act, which imposed heavy fines for noncompliance.¹⁹ Riots erupted across the country, leading to the act's repeal and replacement with a much less restrictive, less coercive mandate. In the context of known violence against EVD clinics in the DRC,⁵ potential backlash against a harsh mandate requiring an experimental vaccine must be considered seriously.

Although mandates work well in some countries, they can also cause backlash, resistance, and resentment. When enforcement capacity is limited or nonexistent, mandates cannot be properly implemented and are thus unlikely to promote public health and safety. Moreover, mandates can backfire if a population resents being coerced and has not received sufficient education about the safety, efficacy, and public health importance of vaccinations. The WHO's Strategic Advisory Group of Experts correctly recognized the value of public education, especially in the DRC, when it included the implementation of a mass communications campaign as one of its key recommendations on Ebola vaccination in the region.²⁰ Thus coercive mandates are not substitutes for educational campaigns²¹; any promotion of

the Ebola vaccine in the DRC should be sure to include education as a key centerpiece, even when more coercive initiatives are utilized.

Conclusion

Evidence suggests that the recently developed Ebola vaccine is an effective and important tool for controlling outbreaks and future pandemics. But resistance to vaccines is also pervasive in some regions, including in the DRC, as suggested by a pattern of violence against vaccine providers.⁵ Legal approaches to compelling vaccination are well established and globally widespread, so restricting individual liberty by mandating vaccination in this context would not be ethically inappropriate or novel. Policymakers, however, should apply the criteria outlined above to assess whether and when a mandate is ethically justified.

References

1. Concern Worldwide US. Ebola outbreak in DRC: second largest outbreak in history ranges in Congo. <https://www.concernusa.org/story/ebola-outbreak-in-drc/>. Accessed October 7, 2019.
2. National Institute of Allergy and Infectious Diseases, National Institutes of Health. Ebola vaccines. <https://www.niaid.nih.gov/diseases-conditions/ebola-vaccines>. Updated February 26, 2016. Accessed September 2, 2019.
3. World Health Organization. Preliminary results on the efficacy of rVSV-ZEBOV-GP Ebola vaccine using the ring vaccination strategy in the control of an Ebola outbreak in the Democratic Republic of the Congo: an example of integration of research into epidemic response. <https://www.who.int/csr/resources/publications/ebola/ebola-ring-vaccination-results-12-april-2019.pdf?ua=1>. Updated April 12, 2019. Accessed June 20, 2019.
4. Human Rights Watch. Democratic Republic of Congo: events of 2018. <https://www.hrw.org/world-report/2019/country-chapters/democratic-republic-congo>. Accessed September 2, 2019.
5. Branswell H. Ebola response teams scrambling to care for patients after attacks set back efforts. *STAT*. March 1, 2019. <https://www.statnews.com/2019/03/01/ebola-response-teams-scrambling-to-care-for-patients-after-attacks-set-back-efforts/>. Accessed June 20, 2019.
6. Winsor M. Ebola outbreak spreads to 3rd province in eastern Democratic Republic of Congo. *ABC News*. August 19, 2019. <https://abcnews.go.com/International/ebola-outbreak-spreads-3rd-province-eastern-democratic-republic/story?id=65051770>. Accessed October 7, 2019.
7. Weithorn LA, Reiss DR. Legal approaches to promoting parental compliance with childhood immunization recommendations. *Hum Vaccines Immunother*. 2018;14(12):1610-1617.
8. National Conference of State Legislatures. States with religious and philosophical exemptions from school immunization requirements. <http://www.ncsl.org/research/health/school-immunization-exemption-state-laws.aspx>. Updated June 14, 2019. Accessed September 2, 2019.

9. *Jacobson v Massachusetts*, 197 US 11 (1905).
10. Annas GJ. *The Rights of Patients*. 3rd ed. Carbondale, Ill: Southern Illinois University Press; 2004.
11. Jobe KM. The constitutionality of quarantine and isolation orders in an Ebola epidemic and beyond. *Wake Forest Law Rev*. 2016;51:165, 172-180.
12. Attwell K, Navin M. How other countries get parents to vaccinate their kids (and what Australia can learn). *Medical Xpress*. September 18, 2019. <https://medicalxpress.com/news/2019-09-countries-parents-vaccinate-kids-australia.html>. Accessed October 4, 2019.
13. Mello MM, Studdert DM, Parmet WE. Shifting vaccination politics—the end of personal-belief exemptions in California. *N Engl J Med*. 2015;373(9):785-787.
14. France makes 11 child vaccines compulsory: no vaccines, no school. *EFE*. January 2018. <https://www.efc.com/efe/english/technology/france-makes-11-child-vaccines-compulsory-no-school/50000267-3480979>. Accessed October 4, 2019.
15. Meldrum M. “A calculated risk”: the Salk polio vaccine field trials of 1954. *BMJ*. 1998;317(167):1233-1236.
16. Brandon DT, Isaac LA, LaVeist TA. The legacy of Tuskegee and trust in medical care: is Tuskegee responsible for race differences in mistrust of medical care? *J Natl Med Assoc*. 2005;97(7):951-956.
17. Centers for Disease Control and Prevention. Tuskegee Study, 1932-1972. <https://www.cdc.gov/tuskegee/index.html>. Updated December 14, 2015. Accessed September 2, 2019.
18. Atwell K, Navin MC, Lopalco PL, Jestin C, Reiter S, Omer SB. Recent vaccine mandates in the United States, Europe, and Australia: a comparative study. *Vaccine*. 2018;36(48):7377-7384.
19. Wolfe RM, Sharp LK. Anti-vaccinationists past and present. *BMJ*. 2002;325(7361):430-432.
20. Strategic Advisory Group of Experts (SAGE) on Immunization. Interim recommendations on vaccination against Ebola virus disease (EVD). https://www.who.int/immunization/policy/position_papers/interimEbola_recommendations_may_2019.pdf?ua=1. Updated May 7, 2019. Accessed September 2, 2019.
21. Leask J, Danchin M. Imposing penalties for vaccine rejection requires strong scrutiny. *J Pediatr Child Health*. 2017;53(5):439-444.

Carmel Shachar, JD, MPH is the executive director of the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School in Cambridge, Massachusetts, where she is also a lecturer on law at Harvard Law School. In addition to running the center’s research and programmatic efforts, she is interested in access to care, the right to health, value-based health care structures, and public health concerns

Dorit Rubinstein Reiss, LLB, PhD is a professor of law and the James Edgar Hervey ‘50 Chair of Litigation at the University of California, Hastings College of the Law, in San Francisco. Her research and activities are increasingly focused on legal and policy issues related to vaccines, such as school

mandates, policy responses to nonvaccinating, tort issues, and administrative issues related to vaccines.

Citation

AMA J Ethics. 2020;22(1):E36-42.

DOI

10.1001/amajethics.2020.36.

Conflict of Interest Disclosure

Dorit Reiss' family owns regular stock in GSK, a vaccine manufacturer. Carmel Shachar had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

STATE OF THE ART AND SCIENCE

Making Emergency Use of Experimental Vaccines Safer

Archana Asundi, MD and Nahid Bhadelia, MD

Abstract

Ethical and logistical challenges of deploying experimental vaccines in humanitarian emergencies are exacerbated by a paucity of safety and efficacy data. For outbreaks caused by pathogens with high mortality rates and few treatments, such as Ebola virus disease, not offering access to experimental vaccines with some evidence of efficacy can also be ethically suspect. This article recommends (1) gathering more preclinical data about experimental vaccines' safety and (2) improving research infrastructure to enable participation of a wide range of subjects in affected communities over long trial periods. Motivating these goals would facilitate clearer definitions of *population vulnerability* and *risk acceptability*.

Risk of Disease vs Risk of Experimental Vaccination

Safe and effective vaccination programs are critical to mitigating disease outbreaks, but vaccine deployment can be fraught with logistical challenges and ethical questions that vary with the environments in which programs are implemented. Effectively deploying experimental vaccines for emerging infectious diseases relies on policy and research infrastructure to ensure safe, ethical research during emergencies. The complexity of these challenges was apparent during the management of recent Ebola virus disease (EVD) epidemics. At the time of the 2013-2016 West African outbreak, effective management was hampered by, among other things, a lack of licensed vaccines and treatments to deploy to control EVD.^{1,2} In the midst of global community members' push to initiate clinical trials for experimental vaccines and therapeutics, discussions arose about which criteria should be used to distribute experimental vaccines among vulnerable groups, particularly those in resource-limited settings.³ The current North Kivu EVD outbreak in the Democratic Republic of the Congo (DRC) suggests a continuing need to consider distribution criteria and to develop strategies for anticipating and addressing ethical and logistical questions.

During recent EVD outbreaks, whether experimental recombinant vesicular stomatitis virus-based vaccine (rVSV-ZEBOV) should be used in pregnant and lactating women and in children under one year of age has raised ethical questions. During the 2013-2016 West African Ebola epidemic, members of these populations were excluded from Ebola ça Suffit! trials.⁴ Although the World Health Organization (WHO) Research Ethics Review Committee guided implementation of trials during that outbreak and requested amendments to the protocol to include members of these populations as subjects, it later

relented, as further review was seen as delaying trial initiation and “potential benefit for all.”⁵ In 2019, the DRC National Ethics Committee approved inclusion of pregnant or lactating women and children in a large experimental rVSV vaccination campaign that was underway but required close follow-up and limited distribution to areas where Ebola was being actively transmitted.⁶ This committee’s decision highlights that comparing vulnerable community members’ risk of harm from EVD to their risk of harm from rVSV tends to be considered in decisions about whether, where, and with whom to use experimental vaccines.

A first question to ask about experimental vaccine administration among vulnerable populations in emergent situations is this: How should the concept of vulnerability be defined? Individual, social, cultural, and scientific variables should be prioritized in a definition of this concept and considered with reference to a specific situation or circumstance. We argue that members of vulnerable populations can more safely participate in experimental vaccine trials that (1) gather preclinical data and (2) bolster research infrastructure that enables diverse enrollment and long-term follow-up.

Defining Vulnerability

In research ethics, a vulnerable population is generally thought to be one whose members’ ability to consent to participate in a research protocol is compromised (eg, through lack of competency, illiteracy, poverty, or inability to communicate). A Canadian Tri-Council Policy Statement (TCPS2) more generally defines vulnerability as “diminished ability to fully safeguard one’s own interests in the context of a specific research project” due to “limited decision-making capacity or limited access to social goods, such as rights, opportunity, and power.”⁷ Vulnerability “may require greater effort to minimize risks to participants and/or maximize potential benefits” in order that they be treated justly.⁸

Applying this definition of vulnerability responsibly requires considering that observers can differ in their perceptions of a subject’s moral agency.⁹ For example, during an outbreak, individuals or communities might not perceive themselves as vulnerable, although regulatory bodies or health care organizations do, and vice versa. Moreover, simply identifying characteristics that confer “vulnerability” can also be challenging largely because they can consist of both individual traits—including young age, ethnicity, race, gender, or general or mental health status—and particular contexts that apply to an entire community.

How we define vulnerability shapes how those seen as vulnerable are treated and influences opportunities they are offered. As examples, the Ebola ça Suffit! trial prioritized vaccination for subjects exposed to the virus who were not pregnant, breastfeeding, or severely ill; other trials have included health care workers as subjects, excluding pregnant or lactating women.⁴ More often than not, members of populations considered vulnerable are excluded from clinical trials.¹⁰ Although pregnant women tend to suffer high mortality from EVD,¹¹ they and members of other groups have been excluded from clinical EVD trials.¹¹ Recently, there has been a shift toward not labeling populations as vulnerable,^{11,12} but removing protections justly and equitably requires input

and buy-in from members of these populations, which is difficult to accomplish during an outbreak.

EVD outbreaks have occurred—and continue to occur—in settings fraught with armed conflict and displacement,¹⁴ which exacerbate individuals' and communities' vulnerability. Postconflict food insecurity and lack of health care infrastructure in West Africa likely heightened susceptibility to EVD during the 2014 epidemic and helped propagate it.^{15,16} These conditions persist in the ongoing epidemic in the DRC, where conflict has made tracing contacts difficult, complexified vaccine investigation, and led some to switch to mass vaccination strategies. Such factors must contextualize how we define and understand concepts such as *vulnerability* and even *emergency*, which the WHO defines as the co-existence of outbreak along with either a man-made or natural condition that could cause disruption to health care services.¹⁷ Since context can be dynamic, the process of defining key concepts should also be dynamic. Therefore, international and local agencies should develop close relationships with communities to keep abreast of geopolitical shifts that might influence assessments of vulnerability.

The state of medical science related to emerging diseases like EVD also matters to how vulnerability is defined. A change in clinical standards of care for a particular disease that alters the risk-benefit profile used in individuals' and agencies' decision making should also be regarded as a key variable in understanding and defining vulnerability. For example, populations' susceptibility to EVD during the 2013–2016 epidemic largely hinged on lack of alternatives to **experimental drugs** to prevent and treat EVD, which likely affected subjects' decision making about whether to participate in trials. New therapeutic and investigational vaccines have emerged since then,¹⁸ which have altered risk-benefit profiles of communities undergoing an epidemic and will likewise critically shape conceptions of vulnerability. The changing medical context suggests the importance of determinations of vulnerability being made and reassessed continuously by regulatory committees or global health organizations with regular input from affected communities.

Inclusion and Safety

Several reports, including a recent review by the Pregnancy Research Ethics for Vaccines, Epidemics, and New Technologies (PREVENT) Working Group, highlight how exclusion of vulnerable groups, including pregnant women and children, from research can result in their not having access to experimental vaccines during emergencies.¹⁹ This report's key recommendations for including pregnant women in vaccine research set good milestones to follow for research with other vulnerable populations, however defined in a particular situation.

1. *Gather preclinical data on safety of experimental vaccine use in vulnerable populations.* The PREVENT group recommends using advanced technology to study immune responses of pregnant women and children and recommends creation of market incentives to include vulnerable subgroups in research.¹⁹ These efforts should also seek to augment knowledge about use of experimental vaccines in persons

with HIV and highly prevalent co-infections that might lead to biological vulnerability to disease.⁶

2. *Enable safe enrollment of vulnerable subjects in vaccine trials during crises.* Reports have stressed the importance of building surveillance and health information systems to allow improved capture of the outcomes of experimental vaccine deployment, particularly in vulnerable populations.^{19,20} Aside from strengthening national health systems, building research capacity in countries where Ebola and other pathogens on the WHO's priority diseases list pose risk can motivate safe deployment of experimental vaccines during outbreaks.²¹ A review of clinical trials conducted during the 2013-2016 EVD epidemic by a committee of the National Academies of Sciences, Engineering, and Medicine suggests the importance of long-standing research engagement to enable timely deployment of investigational agents in communities at risk.²²
3. *Cultivate long-term, trusting relationships.* The WHO has developed a framework for ethical decision making concerning use of experimental vaccines during emergencies.^{17,23} In addition, perceptions of risks and benefits of groups considered to be vulnerable should inform community participation strategies. One recent study found that many subjects in an Ebola vaccine trial were motivated by altruism, curiosity, hope, health seeking, and notions of exchange.²⁴ Understanding the role of these values in subjects' decisions about whether to enroll in a protocol suggest that engagement with local leaders and decision makers is key when discussing experimental vaccine deployment in an emergency and is critical for motivating trust. Due to mistrust, 2 Ebola vaccine trials were suspended in Ghana.²⁵

Conclusions

Ethical questions about deploying experimental vaccines during recent and ongoing EVD outbreaks are complex and multifaceted and require attention to dynamic context. Navigating collaborative responses to these questions is aided by contextualizing definitions of *vulnerability* and *emergency*; preparedness; nourishing ongoing and sustainable partnerships with people in local communities where outbreaks tend to recur, including through developing trusting communication; and investing in research infrastructure.

References

1. Kaner J, Schaack S. Understanding Ebola: the 2014 epidemic. *Global Health*. 2016;12(1):53.
2. Cenciarelli O, Pietropaoli S, Malizia A, et al. Ebola virus disease 2013-2014 outbreak in West Africa: an analysis of the epidemic spread and response. *Int J Microbiol*. 2015;2015:769121.
3. World Health Organization. (WHO) Ethical considerations for use of unregistered interventions for Ebola viral disease: report of an advisory panel to WHO.
https://apps.who.int/iris/bitstream/handle/10665/130997/WHO_HI_S_KER_GHE_14.1_eng.pdf;jsessionid=6AD0D5B55A7075578987E6

- [9693C22B7C?sequence=1](#). Published 2014. Accessed November 11, 2019.
4. Henao-Restrepo AM, Camacho A, Longini IM, et al. Efficacy and effectiveness of an rVSV-vectored vaccine in preventing Ebola virus disease: final results from the Guinea ring vaccination, open-label, cluster-randomised trial (Ebola Ca Suffit!). *Lancet*. 2017;389(10068):505-518.
 5. Alirol E, Kuesel AC, Guraiib MM, de la Fuente-Nunez V, Saxena A, Gomes MF. Ethics review of studies during public health emergencies—the experience of the WHO ethics review committee during the Ebola virus disease epidemic. *BMC Med Ethics*. 2017;18(1):43.
 6. Strategic Advisory Group of Experts (SAGE) on Immunization. SAGE interim recommendations on vaccination against Ebola virus disease (EVD). <https://www.who.int/immunization/interimEbolaRecommendationsFeb2019.pdf>. Published February 20, 2019. Accessed November 11, 2019.
 7. da Silva RE, Amato AA, Guilhem DB, de Carvalho MR, Lima EDC, Novaes M. Factors contributing to exacerbating vulnerabilities in global clinical trials. *Front Pharmacol*. 2017;8:999.
 8. Canadian Institutes of Health Research; Natural Sciences and Engineering Research Council of Canada; Social Sciences and Humanities Research Council of Canada. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. <http://www.frqnt.gouv.qc.ca/documents/10191/186009/TCP52.+pdf/6a8ab915-431b-428d-aa86-b22ca5c78053>. Published 2014. Accessed October 8, 2019.
 9. Levine C, Faden R, Grady C, et al. The limitations of “vulnerability” as a protection for human research participants. *Am J Bioeth*. 2004;4(3):44-49.
 10. Spong CY, Bianchi DW. Improving public health requires inclusion of underrepresented populations in research. *JAMA*. 2018;319(4):337-338.
 11. Gomes MF, de la Fuente-Núñez V, Saxena A, Kuesel AC. Protected to death: systematic exclusion of pregnant women from Ebola virus disease trials. *Reprod Health*. 2017;14(suppl 3):172.
 12. van der Zande ISE, van der Graaf R, Oudijk MA, van Delden JJM. Vulnerability of pregnant women in clinical research. *J Med Ethics*. 2017;43(10):657-663.
 13. Task Force on Research Specific to Pregnant Women and Lactating women, US Department of Health and Human Services. *Report to Secretary, Health and Human Services, Congress*. https://www.nichd.nih.gov/sites/default/files/2018-09/PRGLAC_Report.pdf. Published September 2018. Accessed November 11, 2019.
 14. McPake B, Witter S, Ssali S, Wurie H, Namakula J, Ssengooba F. Ebola in the context of conflict affected states and health systems: case studies of Northern Uganda and Sierra Leone. *Confl Health*. 2015;9:23.

15. Stanturf JA, Goodrick SL, Warren ML Jr, Charnley S, Stegall CM. Social vulnerability and Ebola virus disease in rural Liberia. *PloS One*. 2015;10(9):e0137208.
16. Coltart CE, Lindsey B, Ghinai I, Johnson AM, Heymann DL. The Ebola outbreak, 2013–2016: old lessons for new epidemics. *Philos Trans R Soc Lond B Biol Sci*. 2017;372(1721):20160297.
17. World Health Organization. *Vaccination in Acute Humanitarian Emergencies: A Framework for Decision Making*. <https://apps.who.int/iris/bitstream/handle/10665/255575/WHO-IVB-17.03-eng.pdf?sequence=1>. Published May 2017. Accessed November 11, 2019.
18. Dhama K, Karthik K, Khandia R, et al. Advances in designing and developing vaccines, drugs, and therapies to counter Ebola virus. *Front Immunol*. 2018;9:1803.
19. Krubiner CB, Faden RR, Karron RA, et al. Pregnant women and vaccines against emerging epidemic threats: ethics guidance for preparedness, research, and response [published online ahead of print May 3, 2019]. *Vaccine*.
20. Jacobsen KH, Aguirre AA, Bailey CL, et al. Lessons from the Ebola outbreak: action items for emerging infectious disease preparedness and response. *Ecohealth*. 2016;13(1):200–212.
21. World Health Organization. Prioritizing diseases for research and development in emergency contexts. <https://www.who.int/blueprint/priority-diseases/en/>. Updated February 6, 2018. Accessed July 18, 2019.
22. Keusch G, McAdam KPWJ, Cuff PA, Mancher M, Busta ER, eds; National Academies of Sciences, Engineering, and Medicine. *Integrating Clinical Research into Epidemic Response: The Ebola Experience*. Washington, DC: National Academies Press; 2017.
23. Moodley K, Hardie K, Selgelid MJ, et al. Ethical considerations for vaccination programmes in acute humanitarian emergencies. *Bull World Health Organ*. 2013;91(4):290–297.
24. Tengbeh AF, Enria L, Smout E, et al. “We are the heroes because we are ready to die for this country”: participants’ decision-making and grounded ethics in an Ebola vaccine clinical trial. *Soc Sci Med*. 2018;203:35–42.
25. Kummervold PE, Schulz WS, Smout E, Fernandez-Luque L, Larson HJ. Controversial Ebola vaccine trials in Ghana: a thematic analysis of critiques and rebuttals in digital news. *BMC Public Health*. 2017;17(1):642.

Archana Asundi, MD is a postdoctoral research fellow in the Section of Infectious Diseases at Boston University School of Medicine in Massachusetts, where she coordinates and oversees the conduct of studies concerning HIV translational research at the Center for Infectious Diseases at Boston Medical Center.

Nahid Bhadelia, MD is an assistant professor in the Section of Infectious Diseases at Boston University School of Medicine in Massachusetts, where she is also the medical director of the Special Pathogens Unit. She oversees the medical response program for Boston University’s maximum containment

biosafety level 4 program at the National Emerging Infectious Diseases Laboratories and previously served as a clinician in several Ebola treatment units during the West African epidemic.

Citation

AMA J Ethics. 2020;22(1):E43-49.

DOI

10.1001/amajethics.2020.43.

Conflict of Interest Disclosure

Dr Asundi is an investigator for studies sponsored by Merck and Gilead Sciences. Dr Bhadelia had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2020 American Medical Association. All rights reserved.
ISSN 2376-6980

POLICY FORUM

How Should Global Health Security Priorities Be Set in the Global North and West?

Abraar Karan MD, MPH, DTM&H

Abstract

Epidemics threaten all countries, yet epidemic responses are not implemented in all countries. One reason why is that transnational disease containment efforts (to keep diseases from spreading across borders) differ in important ways from efforts to protect those in countries where an epidemic is active. This article explores these 2 approaches to global health security and suggests reasons to reconsider prioritizing the former first.

Who Is Threatened Matters More

Advances in transportation and increasing numbers of people [travelling internationally](#) mean a disease outbreak in Western or Central Africa can reach Europe or the Americas quickly. The potential for rapid spread of a pathogenic threat as deadly as Ebola suggests the importance of asking how we set global health security priorities and what their implications are. For instance, death rates from Ebola during 2014 and 2015 were about 19% in the United States and Europe and 28% to 75% in West and Central Africa.^{1,2} These figures suggest that global health security has been less about a pathogen's virulence than who is threatened by it. Although pandemics don't regard transnational borders, responses to pandemics certainly do, and these responses will be interrogated and investigated here.

Let's first consider responses to the ongoing Ebola epidemic, which started in 2018 in the Democratic Republic of the Congo (DRC). It is unclear whether this epidemic would have made headlines and garnered international attention if the West African epidemic a few years earlier had not penetrated the borders of Europe or America. Accordingly, one might wonder whether and to what extent prioritizing containment of Ebola in the DRC is a function of how we (those of us in the global North and global West) perceive the risk of Ebola becoming a transcontinental pandemic.

One might suppose that how threatened "we" feel corresponds in some ways to how robust our clinical—and generous our financial—responses are to Ebola epidemics abroad. Two facts should figure prominently in our investigation of this set of issues. First, there have been 10 Ebola outbreaks in the DRC since 1976,² none of which garnered nearly as much global media coverage as Ebola incidents in Europe and North America. Most past Ebola outbreaks have been in the DRC but transpired without major spread beyond

its borders, occurred among small populations, lacked high transmissibility (since they were not concentrated in major cities), and tended to end as infected community members died.² In short, these Ebola outbreaks had low risk of spreading outside the DRC. Second, war in the DRC—along with malnutrition and the spread of infectious disease—killed about 45 000 people per month and more than 5 million people total between 1998 and 2007,³ but received little global media attention.⁴ If security efforts are centered on how many lives are lost, why did war, malnutrition, and disease in the DRC not generate as much global concern as Ebola? How should this source of puzzlement inform our thinking about what we owe the global community and regions navigating outbreaks?

Conceiving Health Security Priorities

Reconsidering what we owe the global community and affected regions means reconceiving what we think of as global health security priorities. Pandemics expert David Heymann and colleagues distinguish between 2 such priorities: individual health security (that of individual people regardless of where they live) and collective health security (that of nation-states defined by their borders). They argue that though they traditionally have been seen as separate, these 2 priorities are inextricably intertwined⁵ because without individual health security there is functionally no collective health security. When we deploy a vaccine as a containment effort, for example, if we cannot guarantee access to the vaccine for each person, we risk spread of the disease, which can put an entire nation or region at risk of a pandemic or an epidemic of that disease. Smoking is another example of how the two are linked: if individual smokers are not treated and their behaviors modified, others will continue to suffer negative health effects of secondhand smoke exposure. This relationship holds for any behavior that causes both primary harms and widespread negative consequences and illustrates a pragmatic reason for focusing first on individual, rather than collective, health security.

Prioritizing collective health security enables *us* (the global North and global West) to justify prioritizing our own (collective) health interests. In doing so, we **neglect the health interests** of people in poor regions of the world—to their systematic detriment and exploitation—often for pragmatic (eg, financial, safety) and political reasons. In the specific example of Ebola, the pragmatic and political reasons are clear: sending US troops or public health workers to the DRC is costly and dangerous; focusing on keeping Ebola out of the United States, even if that means that Ebola stays in the DRC, is politically beneficial for the current administration. However, from a public health standpoint, these reasons are overstated and run the risk of distracting us from what is needed most: treating Congolese victims of the disease. Ebola has a lower R-naught (ie, average number of people that one infected person will likely infect) than most other common infectious diseases that we in the global North and global West regularly encounter, such as the common flu. Given North America's low population density compared to that of sub-Saharan Africa, the chance of a major and uncontrolled Ebola outbreak in the United States is low.

In past situations in which collective health security has been prioritized, pragmatism has proved dangerous: it has translated into wealthy countries

standing idly by as people in poorer global regions die. While one might argue that, from a collective health security standpoint, these lives are not the responsibility of wealthy countries, this argument is morally reprehensible. An ethics lens is needed to complement such pragmatism and can help us here, as there is a clear ethical imperative to protect the health of individuals, regardless of where they live.

Ethical Commitment to Health for All

Thus far, we have mainly referred to collective health security as the health of nation-states and individual health security as the health of individuals regardless of any larger so-called collective of which they are a part. An ethical argument for why the health of a child in the DRC suffering from Ebola is the responsibility of all clinicians worldwide is that it is unethical to differentiate what people deserve based on geographic or political boundaries, ability to pay, or whether those affected are *us* or *them*. In US emergency rooms, clinicians are not allowed to differentiate among patients suffering health emergencies⁵; the ethical principle of beneficence demands that no patient be denied emergency care.

Pandemic response is, globally speaking, emergency care. Upholding the principle of global beneficence during pandemics broadens our understanding of collective health security. This does not mean that every clinician should fly to the DRC tomorrow, but it does mean that clinicians who are part of global health programs and organizations (eg, academic, governmental, private) should regard an Ebola epidemic in ethical terms, not just in pragmatic terms, and as a call to which we are obligated to respond wherever it occurs, given our abundant resources and relative global wealth and power.

Strategies for Ethical Global Health Security

Several strategies that regard all lives as equally important regardless of nation-state boundaries can promote [global beneficence](#) and inclusive health security. These strategies cannot be comprehensively explored in this paper. Nonetheless, individual physicians can promote global beneficence and inclusive health security by making donations of medical supplies and medications; providing telehealth to help aid management of disease remotely; raising funds to help financially support health systems capacity; and facilitating on-the-ground management by working with humanitarian agencies, including Doctors Without Borders, the World Health Organization, or the Red Cross, to name a few.

Longer term and at a systems level, these strategies demand the building and continued support of strong primary health care infrastructure with local leadership. Pandemics have traditionally been seen as unpredictable, acute events but, to better prepare for them, responders must not fall into the trap of a vertical response and instead horizontally address the health system that is treating them. With primary health care systems founded on trust among clinicians and community members, outbreaks would likely be stopped quickly and regionally. Transmission chains could be more easily followed; ring vaccination would be less susceptible to failure; cases could be detected earlier; and patients would be more amenable to treatment. Primary health care models in wealthy countries might help inform, at a very basic level, what

primary health care could look like in impoverished regions, although its instantiation would be very different. As useful as infrastructure support is, even more important—particularly in acute settings—is provision of financial support for pandemic response. In emergency situations, financial resources and access to care are linked: wealthy nations can help ensure adequate response measures by contributing equipment, medications, vaccines, and laboratory services.

A third strategy should focus on **bolstering health care quality**, although this can be difficult to achieve in the acute emergency setting. Studying past pandemics could help generate data on outcomes and on the efficacy of various public health strategies. Unfortunately, without such data, we are shooting in the dark, hoping experimental therapies will work and not cause harm. Furthermore, improving the quality of response depends on pandemic experts (eg, clinicians, epidemiologists, attorneys, and anthropologists) collaborating with local leaders. Accordingly, wealthy nations must not only support but also encourage needed experts to participate in international response, providing them with the security, funds, and organizational capacity to be of service at short notice.

If the global community and its actors are responsible for the failure of individual health security, they should pursue a fourth implementation strategy that focuses on accountability measures for high-income countries. Such measures might include financial penalties or future financial commitments in the form of a progressive global tax to contribute to infrastructure and capacity building in poorer regions.

Although wealthy countries may have considered the containment of the 2014–2016 West African Ebola epidemic to be a global health security “success” because very few cases escaped the continent, it was in reality a failure. More than 11 000 Africans died.² Today, the same tendency to prioritize collective over individual security remains in the DRC. While the WHO’s efforts have contained Ebola within the DRC and now Uganda,² the death toll is the second largest of any Ebola epidemic—more than 2000 lives.⁶ This death toll expresses a failure of individual health security and, as such, a failure of collective health security. Global beneficence demands that protection of human life should supersede protection of nations, borders, international relations, and politics. The global health community’s failure to prioritize beneficence and individual health security is ethically unacceptable.

References

1. Uyeki TM, Mehta AK, Davey RT Jr, et al; Working Group of the US-European Clinical Network on Clinical Management of Ebola Virus Disease Patients in the US and Europe. Clinical management of Ebola virus disease in the United States and Europe. *N Engl J Med*. 2016;374(7):636–646.
2. World Health Organization. Ebola virus disease. <https://www.who.int/news-room/fact-sheets/detail/ebola-virus-disease>. Published May 30, 2019. Accessed July 11, 2019.
3. McGreal C. Congo conflict causes 45,000 deaths a month: study. *Guardian*. January 22, 2008.

<https://www.theguardian.com/world/2008/jan/22/congo.chrismcgre>
[al](#). Accessed July 11, 2019.

4. Moszynski P. 5.4 million people have died in Democratic Republic of Congo since 1998 because of conflict, report says. *BMJ*. 2008;336(7638):235.
5. Emergency Medical Treatment and Labor Act (EMTALA), 42 USC §1395dd (1986).
6. DR Congo Ebola deaths top 2000. *BBC News*. August 30, 2019. <https://www.bbc.com/news/world-africa-49521739>. Accessed October 22, 2019.

Abraar Karan MD, MPH, DTM&H is an internal medicine resident in the Doris and Howard Hiatt Residency in Global Health Equity and Internal Medicine at Brigham and Women's Hospital in Boston, Massachusetts.

Editor's Note:

Background image by Paul Dolan.

Citation

AMA J Ethics. 2020;22(1):E50-54.

DOI

10.1001/amajethics.2020.50.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2020 American Medical Association. All rights reserved.
ISSN 2376-6980

AMA Journal of Ethics®

January 2020, Volume 22, Number 1: E55-60

MEDICINE AND SOCIETY

What Should Health Science Journalists Do in Epidemic Responses?

Katherina Thomas and Alpha Daffae Senkpeni

Abstract

Journalists have long covered outbreaks of infectious disease. In the history of global health journalism—from the 1721 Boston smallpox epidemic to the 2002–2003 SARS outbreak in China and Singapore and to recent outbreaks of Ebola in West Africa and the Democratic Republic of the Congo—newsrooms have wielded their power both responsibly and irresponsibly. This article examines journalism practice during the 2013–2016 Ebola epidemic and recommends strategies for improving epidemic reporting.

Going Viral

Outbreaks of infectious disease are not only public health crises but also crises of information. Journalists have at times both built and undermined public trust, serving as both a constructive source of scientific facts and as a destructive source of rumor that tends to amplify panic. The stakes are now higher than ever before: epidemics now spread not only physically but also digitally, in print, posts, and videos that “go viral.”¹ These media can influence health-seeking behaviors and feed hearsay that can spread as fast as a pathogen. Although there have been many cases of responsible and helpful journalistic coverage of Ebola crises during the last 6 years, some international, national, and local media have hindered humanitarian and clinical response efforts with sensationalist reporting,² eroding trust among clinicians, journalists, and the public, and contributing to the institutional climate of fear that influences community-level avoidance of treatment and attacks on health workers.³ Given the potentially harmful effects of poor epidemic reporting, journalism has a responsibility to contribute to enhanced public knowledge during times of pervasive fear. This article suggests the need for clear professional guidelines informed by both journalistic and health care ethics and educational resources for reporters who cover epidemics.

Poor Reporting of 2013–2016 Ebola Outbreak

When Ebola reached Liberia in 2014, few Liberian journalists with knowledge of health or science reporting were actively reporting in the country.⁴ In the absence of up-to-date medical knowledge, local reporters were susceptible to rumors circulating in social media and on the streets, and local editors relied on decades-old information from outbreaks in the Democratic Republic of the Congo. Some local editors generated or validated conspiracy theories that the outbreak was manufactured to raise money.⁵ Daniel Nyakonah, then-Secretary General of the Press Union of Liberia, related that reporting had become far-fetched and that journalists were embroiled in a “coverage of

chaos” (oral communication), by which he seemed to suggest that some Liberian reporters were producing sensationalist, contradictory, or poorly researched news articles. Later, Nyakonah would learn that “you cannot guess on science and health reporting as a journalist” (oral communication). Although local journalists lacked scientific knowledge, they were well placed to tap into cultural context and reach local audiences.

Meanwhile, international journalists were flown into the epicenter of the 2013-2016 Ebola outbreak without adequate training or contextual knowledge. Like their local counterparts, some foreign correspondents were not experienced in Ebola reporting; debates emerged, for example, about whether journalists should wear gloves and gumboots,⁶ which can be risky for those not trained in donning and doffing personal protective equipment. News organizations, including the British Broadcasting Corporation, used stringent risk assessment measures.⁷ Moreover, coverage of the outbreak was limited. Some international reporters failed to include perspectives of local populations in their reports because they interviewed only non-African, and disproportionately white American, responders.⁸ Worse, some mainstream US news outlets neglected to cover the outbreak at all, even as case numbers exploded into the thousands. Instead, they ran sensationalist headlines that stigmatized immigrants from unaffected African countries.⁹

Good Journalism Practice During an Epidemic

Given the harms just outlined, we recommend the following strategies for improving epidemic reporting.

Designate an online resource library for best journalism practices during epidemics. This online library might include scientific sources for myth debunking, recommendations for reporting in affected communities, guidelines for preventing spread of stigma, resources for limiting and addressing secondary trauma, training lectures and seminars, and a glossary of relevant scientific and medical terminology. Ideally, an online resource library should be accessible anywhere in the world, regardless of internet speed, and would guide good journalism practices that avoid sensationalism and are free of bias.

Enhance channels of communication between responders and reporters. Ministries of health and international partners should consider how local media might respond to training exercises. For example, in the wake of the 2013-2016 Ebola outbreak in Liberia, a consortium of international nongovernmental organizations staged an Ebola simulation to test response capacity of a county health team and other responders. Within hours, information was leaked to the press, who believed the exercise was not a simulation, but real; news reports sparked public panic.¹⁰ An Ebola training exercise in Sierra Leone in 2019 also reached local journalists and social media, with similar consequences.¹¹ And, as far back as the 1995 Ebola outbreak in Kikwit, Democratic Republic of the Congo (formerly Zaire), “fistfights broke out between scientists and persons in the media. Patient confidentiality was violated. Funerals were invaded by hordes of camera crews.... Some of the media did truly misbehave themselves, as did some of the scientists,”¹² writes the Pulitzer Prize-winning health journalist Laurie

Garrett. These incidents could likely have been avoided with clearer communication.

Engage journalists and responders in trust-building exercises. To restore trust, channels of communication between global public health and journalism sectors, such as those established and maintained by Internews Network¹³ and BBC Media Action,¹⁴ must become more widespread. Health ministries and response organizations can launch these efforts. In the ongoing Ebola outbreak in the Democratic Republic of the Congo, local journalists have registered with designated Ministry of Health-led press associations to gain access to interviewees, while responders use the network to gain access to media when needed. Such networks should also be used to educate responders about journalism ethics and journalists about clinical terminology and health care ethics. Just as clinicians are responsible for maintaining confidentiality of patients' information, so journalists are obliged to protect their sources from harm or stigma and to engage in unbiased reporting.

Make money and equipment available to journalists covering epidemics. About 80% of US newspapers cut their science content between 1989 and 2012, according to the *Columbia Journalism Review*.¹⁵ With plummeting budgets for travel, even the best science reporters are often economically prohibited from covering epidemics. Local journalists already based in an affected country are best placed to fill this gap, but they too lack critical resources (eg, adequate pay and equipment) and are often treated as subordinates by their international counterparts.

View local journalists as colleagues. When international editors commission local journalists to report or photograph, they should offer rates of pay equal to those of international reporters. Local journalists are often better positioned than those at desks in foreign newsrooms to pitch and lead a story, given their deeper understanding of on-the-ground dynamics. Community radio reporters are also underutilized resources for response organizations trying to understand context; during an epidemic, radio can serve as a vital channel for local experts to debunk rumors and share scientific information. Local radio reporters have likely already earned community members' trust, so they can help responders disseminate important information and motivate good health journalism. "Health journalism in Liberia is more than information or entertainment, but a kind of prophylaxis for our listeners" (oral communication), said Foday Sesay, a Liberian community radio journalist who has covered Ebola crises. Partnering with local media motivates goodwill by building inclusion, helping prevent spread of rumors, and establishing local journalists as key links in information chains. During the 2014-2016 West Africa Ebola outbreak, for example, BBC Media Action partnered with local media to produce a weekly radio discussion program in Sierra Leone.¹⁶ Internews Network also worked with community radio reporters in Liberia to debunk rumors live on air.¹⁷

Help responders and clinicians understand that good journalists strive to be allies in navigating an outbreak. Despite past incidents of irresponsible reporting,² most journalists covering outbreaks care as deeply about their work and serving communities as infectious disease clinicians, and they work

at personal risk and for little financial gain. The characteristics of an [ethical, rigorous journalist](#) are not unlike those of a good clinician: truthfulness, integrity, intellectual curiosity, communication skills, and empathy. As Garrett writes, “it is unfair to characterize journalists’ behaviors in such crises as those of award-hungry, prestige-starved monsters. In general, they are no more likely to be so motivated than are the occasional scientists I have met who think of nothing but winning a Nobel Prize.”¹²

Conclusion

Responsibility for establishing and maintaining journalism’s good public image belongs to journalists, who must not take lightly the power they wield during a public health crisis. Nyakonah says that following training and extensive reporting experience, he and members of the Liberian Journalists’ Union are now more confident about telling stories from science-based perspectives and, in so doing, “using our journalism to contribute meaningfully to the survival of the state” (oral communication).

References

1. Towers S, Afzal S, Bernal G, et al. Mass media and the contagion of fear: the case of Ebola in America. *PLoS One*. 2015;10(6):e0129179.
2. Gynes N, Mina AX. How misinfodemics spread disease. *Atlantic*. August 30, 2018.
<https://www.theatlantic.com/technology/archive/2018/08/how-misinfodemics-spread-disease/568921/>. Accessed September 10, 2019.
3. Vinck P, Pham PN, Bindu K. Institutional trust and misinformation in the response to the 2018-19 Ebola outbreak in North Kivu, DR Congo: a population-based survey. *Lancet*. 2019;19(5):529-536.
4. Lu J. Traffic accident? Call a reporter! How journalists are forcing change in Liberia. *Guardian*. October 12, 2017.
<https://www.theguardian.com/working-in-development/2017/oct/12/traffic-accident-call-a-reporter-how-journalists-are-forcing-change-in-liberia>. Accessed September 10, 2019.
5. Feuer A. The Ebola conspiracy theories. *New York Times*. October 18, 2014. <https://www.nytimes.com/2014/10/19/sunday-review/the-ebola-conspiracy-theories.html>. Accessed September 10, 2019.
6. Matloff J. Reporters struggle to stay safe covering Ebola. *Columbia Journalism Review*. October 7, 2014.
https://archives.cjr.org/behind_the_news/dangers_of_reporters_covering.php. Accessed August 2, 2019.
7. Mazumdar T. *Ebola Crisis: How Journalists Protect Themselves While Reporting* [video]. London, UK: BBC News; October 7, 2014.
<https://www.bbc.com/news/av/world-africa-29521201/ebola-crisis-how-journalists-protect-themselves-while-reporting>. Accessed July 10, 2019.
8. French HW. Media perspectives: how does Africa get reported? A letter of concern to *60 Minutes*. In: Bunce M, Franks S, Paterson C, eds. *Africa’s Media Image in the 21st Century: From the “Heart of Darkness” to “Africa Rising.”* London, UK: Routledge; 2017:38-39.

9. Yusuf I, Yahaya S, Qabli S. Role of media in portraying Ebola in and outside Africa. *J Trop Dis*. 2015;3(1):100152.
10. Bailey M. Ebola simulation in three counties gives Liberia health system a failing grade. *Bush Chicken*. March 18, 2019. <https://www.bushchicken.com/ebola-simulation-in-three-counties-gives-liberias-health-system-a-failing-grade/>. Accessed September 2, 2019.
11. Doodoo L. No case of Ebola virus disease in Sierra Leone. *FrontPage Africa*. June 21, 2019. <https://frontpageafricaonline.com/health/no-case-of-ebola-virus-disease-in-sierra-leone/>. Accessed August 30, 2019.
12. Garrett L. Understanding media's response to epidemics. *Public Health Rep*. 2001;116(suppl 2):87-91.
13. Internews website. <https://internews.org/>. Accessed October 3, 2019.
14. Wilkinson S. Using media and communication to respond to public health emergencies: lessons learned from Ebola. London, UK: BBC Media Action; June 2016. <http://downloads.bbc.co.uk/mediaaction/pdf/practicebriefings/ebola-lessons-learned.pdf>. Accessed September 10, 2019.
15. Morrison S. Hard numbers, weird science. *Columbia Journalism Review*. January/February 2013. https://archives.cjr.org/currents/hard_numbers_jf2013.php. Accessed July 30, 2019.
16. BBC Media Action. Kicking out Ebola. <https://www.bbc.co.uk/mediaaction/where-we-work/africa/sierra-leone/sierra-leone-ebola-response>. Accessed October 3, 2019.
17. Internews. Internews celebrates World Radio Day in Liberia by emphasizing the role of media in fighting the Ebola epidemic. <https://internews.org/index.php/updates/internews-celebrates-world-radio-day-liberia-emphasizing-role-media-fighting-ebola-epidemic>. Published February 16, 2016. Accessed October 3, 2019.

Katherina Thomas is visiting writer-in-residence at the Sabeti Lab at the Broad Institute of MIT and Harvard University in Boston, Massachusetts. She earned a BA from the University of Warwick, trained as a journalist on the foreign desk of the *Independent* newspaper, and is completing an MPH at the London School of Hygiene and Tropical Medicine. Her research draws on her decade's experience as a global health journalist and oral historian living and working in sub-Saharan Africa, where she extensively covered the 2013-2016 Ebola outbreak in Liberia, as well as outbreaks of cholera and Lassa fever. She has published articles on infectious diseases, health systems strengthening, and access to health during conflict in the *Guardian*, the *Economist*, *Harvard Public Health Magazine*, the *New York Times*, the *New Yorker*, and other news outlets.

Alpha Daffae Senkpeni is an editor at *FrontPage Africa*, a Liberian daily newspaper, as well as a science journalist and community radio reporter who covered the 2013-2016 West Africa Ebola crisis. He has also presented internationally on the role of journalism and risk communication during outbreaks. He earned a BA in mass communication from the University of

Liberia and a diploma in media studies from Renmin University of China and is completing an LLB at the University of Liberia Louis Arthur Grimes School of Law.

Citation

AMA J Ethics. 2020;22(1):E55-60.

DOI

10.1001/amajethics.2020.55.

Conflict of Interest Disclosure

Both authors have had previous, short-term affiliations with Internews Network—Thomas as a health journalism advisor in 2015-2016 and Senkpeni as an attendee at 2 training courses in Liberia in 2014-2015. However, neither author has worked with or for Internews Network since 2016, and neither anticipates future employment with the organization.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

AMA Journal of Ethics®

January 2020, Volume 22, Number 1: E61-62

ART OF MEDICINE

Burnout

G. Matthew Heenan

Abstract

Multiple pieces of reclaimed pallet wood are sculpted into a lateral cerebrum and a gradient of burned wood visually represents a crisis among health care professionals.

Figure. *Burnout*



Media

Reclaimed pallet wood.

Caption

Like the wood of a tree, health professions students and practitioners grow stronger with each year of study and practice. Although wood is the strength and substance of a tree, allowing its branches and leaves to flourish despite harsh weather, wood also predisposes a tree to burn. *Burnout* is a metaphor for the emotional exhaustion, cynicism, and negligence that can engulf even the strongest students and clinicians.

G. Mathew Heenan earned a bachelor of arts degree in philosophy in 2013 from the University of Missouri-Kansas City and is currently a third-year medical student at the University of Kansas School of Medicine.

Citation

AMA J Ethics. 2020;22(1):E61-62.

DOI

10.1001/amajethics.2020.61.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

AMA Journal of Ethics®

January 2020, Volume 22, Number 1: E63-65

ART OF MEDICINE

Worlds Apart

Tamera Means, MD, MHS

Abstract

Two photographs of caregivers walking through a Honduran jungle to visit patients in their homes literally and figuratively represent barriers to health care access.

Walking miles on Honduran dirt roads and climbing densely forested, steep hills, our team experienced first hand the physical and geographical barriers to health care. We made our way to rural homes of patients unable to make this journey. Clearing the woods, we entered an open field and paused to observe the enormity of the mountain terrain we had just traversed.

Figure 1. The Journey to a Rural Patient's Home



After one week of caring for patients, our pharmaceutical and other medical supplies almost depleted, we found our congestive heart failure patient at the bottom of a mountain, his wheezing granddaughter at his side. We were

prepared for him, but his granddaughter—diagnosed for the first time—was unexpected. We treated both with our limited supply of medication, and, despite our help, their futures would remain uncertain. We left our desire to do more unsated, our heads full of more questions than answers.

Figure 2. Jungle Trail



My hope remains that, through times of persistent uncertainty and resource scarcity, we health professionals find our niche and try to help, both locally and globally.

Tamera Means, MD, MHS earned her medical degree from Meharry Medical College, her master of health science degree from Johns Hopkins School of Public Health, and her bachelor's degree in public health from Johns Hopkins University. Her interests include medical ethics, public health, global medicine, and improving health care, and she aims to educate communities on these issues and inspire medical professionals with a passion for change through her photography.

Citation

AMA J Ethics. 2020;22(1):E63-65.

DOI

10.1001/amajethics.2020.63.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.