

## NEWS IN FOCUS

### Ebola and its Discontents

Elke Mühlberger  
Boston University  
muehlber@bu.edu

Deboleena Roy  
Emory University  
droy2@emory.edu

Pamela Scully  
Emory University  
pamela.scully@emory.edu

Banu Subramaniam  
UMass Amherst  
banu@wost.umass.edu

Jennifer Terry  
University of California, Irvine  
jterry@uci.edu

*As we planned this inaugural issue, and watched the news of Ebola in the U.S. media, we witnessed the epidemic of Ebola happening "out there" and then the ensuing panic when it arrived "here" in the U. S. The coverage was hauntingly similar and yet different. With each global pandemic, we have heard growing cries for a global "management" often tied to circuits of biomedicine, pharmaceuticals, and (inter)national*

Mühlberger, E., Roy, D., Scully, P., Subramaniam, B., and Terry, J. (2015). News in Focus: Ebola and its discontents. *Catalyst: Feminism, Theory, Technoscience*, 1(1), 1-14 <http://www.catalystjournal.org> | 2380-3312

© Elke Mühlberger, Deboleena Roy, Pamela Scully, Banu Subramaniam, & Jennifer Terry, 2015 | Licensed to the Catalyst Project under a Creative Commons Attribution Non-Commercial No Derivatives license

*security. A year later, the many apocalyptic narratives have been laid to rest for the time being, but Ebola remains in the air as an early warning of the epidemic "still to come." We asked three interdisciplinary scholars to reflect on what they saw.*

*~ Curated by Deboleena Roy and Banu Subramaniam*

### **My 'top 6' Ebola terrors**

*Elke Mühlberger, Microbiology, National Emerging Infectious Disease Institute (NEIDL), Boston University, School of Medicine*

The current Ebola virus outbreak has been devastating and terrible in many aspects. As of March 2015, about 25,000 people were reported to be infected and more than 10,000 patients have died. And it is not over yet. This outbreak dramatically demonstrates just what viruses are capable of and how vulnerable we are when we are struck by emerging infectious diseases without being prepared. Besides the terrifying disease itself, there are numerous other disconcerting aspects of this outbreak that have made me shiver. So I came up with a very personal 'top 6' list of Ebola terrors:

*#1 Self-proclaimed Ebola experts.* Simply terrifying. Vocal, annoying and worst of all, frequently wrong. This clearly led to...

*#2 Ebola hysteria.* It was impressive to see how the lack of scientific reasoning and common sense led to a complete misjudgment of the actual risk of becoming infected with Ebola virus. Fear leads to rather creepy and misguided behavior. To give just one example: the stigmatization of people from West Africa at the peak of the hysteria. At times during this outbreak I had a hard time believing that this is the 21st century.

*#3 The transmission debate.* After all these months with Ebola it is clear that this virus does not spread as rampantly as flu or measles. Yet some folks continue to speculate that Ebola virus may become airborne

through just a couple of mutations. Do we know of any other human virus that has managed to change its mode of transmission from bodily fluids to airborne? Not that I am aware of.

#4 *The “out of an abundance of caution” phrase.* An overabundance of caution has likely caused more harm than good. Out of an abundance of caution, poor Excalibur, the perfectly healthy dog of the Spanish nurse infected with Ebola virus, was euthanized, even though there is, and has never been, any indication that dogs can either be infected with or transmit Ebola virus. Out of an abundance of caution, nurses and doctors who risk their lives helping to contain this terrible outbreak are given a cold welcome at home by being put into isolation. And we do this despite the knowledge that Ebola virus is only transmitted from human to human after the onset of symptoms. Sadly, many people who were otherwise willing to volunteer in West Africa did not go because of the threat of being grounded for another three weeks upon their return.

#5 *The Ebola publication flood.* Those of us who actually work on Ebola virus are strongly affected by number 5 on my list—the flood of Ebola publications we have had to wade through during the last couple of months. Don’t get me wrong, it is extremely important to gather as much information as possible about Ebola virus disease. But when hype takes over and scientific rigor is sidelined, this leads to significantly more work and money being spent in the future as scientists pursue or challenge these false leads. And some of these recent publications are of breathtaking uselessness.

#6??? *Good gracious me—What was my number 6?* I guess it was something important. Oh yes, Ebola virus—it causes a terrible disease, has ravaged an already fragile economic system in western Africa, decimated entire families, made children into orphans, and the list goes on and on. But Ebola virus is not the only member in the club of dangerous viruses. Take, for example, measles virus. It is the most contagious human virus we know of. It is immunosuppressive. It kills children. According to the WHO, there were 145,700 measles deaths

globally in 2013. The good news is that we have an effective vaccine to protect against measles virus infection. I have a hard time understanding why parents would put their children's lives in danger by not vaccinating them against such a serious disease that can cause death. Makes me sick. Actually, I think the #1 terror on my list is parents who put their kids (and others) at risk of getting severely ill, even though a safe vaccine is available.

### **Combatting Ebola requires much more than science**

*Pamela Scully, Women, Gender, Sexuality Studies and African Studies, Emory University*

It has been more than a year since Ebola appeared in West Africa, moving stealthily in the tropical forest interior at the borders of Guinea, Sierra Leone, and Liberia, and then rapidly accelerating when it reached the sprawling capital cities of Conakry, Freetown and Monrovia. As we now know, it took some six months for the local and international public health organizations to realize what they were dealing with. Since August 2014 the CDC, WHO, Doctors Without Borders, Partners in Health and others have directed millions to curtailing Ebola. Because of longstanding ties with Liberia, founded by US settlers in the 1820s, at the request of President Ellen Johnson Sirleaf the US sent in the military to establish field hospitals and coordinate operations. While Ebola still ravages much of Guinea and Sierra Leone, it has been halted in Liberia at the time of writing.

What lessons can we learn from this massive outbreak, which has killed over 11,000 people? There are many, from the impoverishment of the capitalist mode of drug discovery and delivery, and the poverty of development agendas which have poured millions of dollars in aid into the war-torn countries hit now by Ebola, but which did not create sustainable public health systems; to the lack of trust between citizens and their governments, and between citizens and medical experts. But here I want to concentrate on Ebola as a gendered and locally contextual disease.

Ebola can be called a woman's disease (Bofu-Tawamba, 2014). Ebola is contracted through bodily fluids. In West Africa, women are responsible for care giving, preparing food, and washing the dead in preparation for burial. And the Ebola dead are particularly virulent. Women are thus highly likely to contract Ebola. The fact that so many people who have died were women, leaves a terrible legacy—thousands of children who no longer have mothers to look after them in societies where that is the key responsibility of women. In addition, the creation of so many orphans has other terrible effects: studies show the prevalence of sexual violence against women and girls in Liberia. Even more alarmingly, a study by MSF showed that nine out every 10 survivors they treated in 2011 were under 18, and one in 10 were under the age of four. We can expect an increase in the vulnerability of girls to rape and other forms of sexual exploitation, including sex trafficking, in the aftermath of Ebola.

To understand Ebola then, we have to look beyond the science and know about how households work and the gendered division of labor in a particular society, in order to understand the impact of the disease and how to stem it.

It is for these reasons that the WHO and others have started looking to communities and to social scientists to understand how to end Ebola (and other similar outbreaks in the future). The Ebola Anthropology Initiative is a collection of social scientists, primarily anthropologists (the author is on the advisory board as a historian), who are in dialogue with the public health community to try and raise important questions around culture and political economy as crucial contexts to understand the disease. The allied Ebola Response Anthropology Forum (<http://www.ebola-anthropology.net>)<sup>1</sup> has created a website that provides thoughtful analyses of local conditions.

Most importantly, these initiatives stress that communities must be at the center of any public health initiative. They have to help direct the work, and not just be told what to do. In Liberia, where Ebola has almost disappeared, this happened not just because of the establishment of

health care facilities, but because communities made changes themselves. People did not abandon their ways of showing care and love for the sick and the dying, but made accommodations. They changed the way they say hallo (no more handshakes) and how they bury their dead: no more laying hands on the dead body.

Ebola has highlighted the failures of the development agenda with short-term goals driven in part by donor demands for quick results. Both local organizations and communities and the bigger funding agencies are trying to rethink the way forward. The Ebola 100 research project is seeking to document the ways in which people at all levels and in different countries tried to address Ebola: this will help us document and understand societal responses to this epidemic. Emory University recently received a grant from the CDC to establish The African Centre of Excellence for Public Health Security in Liberia. The Paul G. Allen Foundation has issued an RFP for innovative proposals, which include social mobilization and community partnerships. Perhaps, these initiatives will be the beginning of more productive and egalitarian ways of working in the world.

### **Ebola and the unequal economy of life**

*Jennifer Terry, Department of Gender & Sexuality Studies, University of California at Irvine*

The Ebola outbreak of 2014 laid bare the reality of an unequal economy of life according to which some lives are valued over others. While thousands of west Africans fell ill and died from the disease over the spring and summer, it wasn't until a small number of white Westerners from the United States and Europe came down with Ebola virus disease (EVD) in late July that authorities with the World Health Organization, USAID, and the U.S. Centers for Disease Control and Prevention began to treat the outbreak like the urgent and deadly crisis that it was. Over the summer of 2014, among the most sympathetically publicized cases of afflicted people featured white, Christian American health care workers,

Kent Brantly and Nancy Writebol, both employed by Samaritan's Purse, a faith-based non-governmental organization headquartered in Boone, North Carolina. Comparing both the disparities in medical treatment and the partiality of publicity surrounding cases of Ebola infection brings to light how some lives are apparently more valued than others. In the midst of this situation the more raw issue of money-making reared its ugly head. I offer two examples to illustrate this: the first has to do with pharmaceutical profiteering akin to what Naomi Klein has called disaster capitalism and the second with revenue-conscious damage control and labor exploitation of nurses by a non-profit medical organization in Texas.

1) British pharmaceutical giant GlaxoSmithKline has in recent years bought up vaccine-makers in anticipation of a growing global market in anti-viral treatments with the emergence of SARS, MERS, EVD and the like. In March 2014, three months into the latest Ebola outbreak, GSK contacted the World Health Organization to announce that it had developed a preclinical Ebola vaccine candidate. Johnson and Johnson announced human clinical trials of an anti-Ebola vaccine in January 2014, partnering with a Danish vaccine maker to accelerate production. Pfizer also jumped into the game around the same time. Mapp Biopharmaceutical, Inc., a relative newcomer and small-scale manufacturer of engineered monoclonal anti-bodies, started to make headlines during the summer of 2014 when the media ratcheted up its panicked coverage. Mapp's product, ZMapp™, was one of a very few anti-viral treatments that showed promise in animal trials but due to a lack of sufficient funds and poor coordination among government agencies and various pharmaceutical companies, there wasn't enough of the drug stockpiled for dealing with last summer's outbreak (The Economist Nov. 1, 2014).

In late July, Zmapp™ was secretly administered to Brantly and Writebol, who were exposed to the Ebola virus while working in a clinic in Monrovia, Liberia. The intravenous treatment was given to the two under the compassionate use exemption of the U.S. Food and Drug

Administration. Both were then airlifted to Emory University Hospital in Atlanta and pronounced cured within weeks of their arrival. Around the same time, doctors with Médecins Sans Frontières (Doctors Without Borders) decided to withhold the same treatment from Dr. Sheik Umar Khan, a beloved Sierra Leonean physician who died in late July after treating many Ebola patients. Khan was never told that Zmapp™ was available (Fofana and Flynn, 2014).

Doctors from Médecins Sans Frontières claimed their decision was based on sound ethical reasoning. They decided it would cause a serious loss of trust among local residents if Khan died from the medication and they decided that if it was effective it would not be fair to give Khan priority treatment while hundreds of other infected people did not have access to the very limited supply of Zmapp.™ Two weeks after Khan's death, the World Health Organization approved several experimental drugs, including Zmapp,™ for treating Ebola virus disease.

2) Financial investment professionals in the United States began to exploit the Ebola scare especially following September 30, 2014, when the first case of Ebola in the United States was officially announced. Following the conventions of what Priscilla Wald has called the contagion narrative (2008), the leading media corporations in the United States made much of the misfortune of Thomas Eric Duncan, a native Liberian who traveled to Dallas from Monrovia in September to visit family members. When Duncan—the Patient Zero in media coverage—came down with a fever several days after his arrival, he sought treatment at the Texas Presbyterian Hospital emergency room. He was sent home with a diagnosis of sinusitis and given a prescription for antibiotics, even though he told the medical staff that he had just arrived from West Africa. Three days later he was back in the emergency room with severe symptoms of Ebola infection. After several hours, the ER staff called the Centers for Disease Control and Prevention in Atlanta. Duncan was finally admitted over 30 hours after this second trip to the ER to a 24-bed intensive care unit that had been emptied of all other patients. A lawsuit filed against the

owners of Texas Presbyterian by Nina Pham, one of the nurses who cared for Duncan, notes that for the next eight days he was cared for by nurses and other medical personnel who were not adequately trained or equipped to handle a patient with Ebola. The suit further charges that the hospital violated Pham's privacy and committed fraud in the accounts it provided to the media (Emily, 2015).

The day after Duncan was formally admitted, the 26-year-old Vietnamese American emergency nurse arrived at work to find that she was being assigned to care for him. When she inquired about safety precautions (since there had been no in-service training at the hospital), her supervisor "went to the Internet, searched Google, and printed off information regarding what Nina was supposed to do, and handed Nina the paper" (Pham vs. Texas Health Resources, Inc., filed in Dallas County Court on March 2, 2015). Despite the fact that there was a biosafety level 4 facility at Galveston National Laboratory—only an hour away by plane—that was equipped to handle Ebola, Texas Health Resources (THR) did not consult the lab, one of only two such labs in the United States. After caring for Duncan with whom she developed great sympathy, Pham was told by her employer that she could go home. Relieved, she invited friends over. Two days after Duncan died, she woke up with a fever and called the hospital to notify them but was told that her 99.8 fever did not meet the threshold the threshold of concern, 100.4. The next day she awoke with a 100.6 fever and called the hospital requesting to be admitted as a "No Information" patient, a precaution to protect her identity from the media. She was taken into isolation when she arrived at the ER for a battery of tests. Hours later, the chief nursing officer entered Pham's room in a full hazmat suit to inform her that she had tested positive for the Ebola virus. She soon also learned that her request for privacy had been violated, with "dozens of people throughout the THR system" having access to her health status and identity (Pham v. THR).

When Pham was transferred to the National Institutes of Health facility in Bethesda, Maryland for further treatment, the THR worried about their reputation and their declining revenue. To make this point more

vividly, right before she was transferred, one of Pham's physicians entered her room wearing a tiny GoPro camera concealed under his hood and commenced to film everything in the room. Though she didn't give him the answers he was seeking, finally her eyes welled up with tears and she made a few optimistic statements. The video was immediately edited to make THR look good and was posted on the organization's YouTube site, despite the fact that Pham had never given her permission to be used in any public relations campaign.

Pham received aggressive treatment at the NIH and was eventually pronounced cured, whereupon she was released and sent directly to the White House for a highly publicized meeting with President Obama. It should be noted that Pham's lawsuit concludes with a word of caution about the claims of medical triumph: the symptoms of anxiety and pain (related possibly to the aggressive experimental treatment she received) persisted well after her release from the NIH, making her unable to return to work.

What can be gleaned from these two interwoven illustrations of who is valued when it comes to deadly infectious disease and who is not? While it may seem encouraging that financial investments for contending with EVD increased over the course of the outbreak of 2014, we learn from locally based health care activists that resources are much better spent by supporting community-based efforts of preventive education, contact tracing, and humane care than the speculative capital that is directed toward expensive and risky pharmaceutical trials. Fostering relationships of trust between health care workers and people in the communities they serve is a much more cost effective way to gain control over infection rates and to care for patients in a manner that honors their dignity and allays social suffering (Mogelson, 2015).

## Notes

<sup>1</sup> The Ebola Response Anthropology Forum (n.d) is a frequently updated online database of articles and information about Ebola. Social scientists

and outbreak response team members from the London School of Health and Tropical Medicine, the Institute of Development Studies, and the universities of Sussex and Exeter produce the forum. The aim of the online database is to foster policy discussion and critical debate while providing rapid responses by e-mail, conference calls and web-based dialogues to operational questions raised by those working for NGOs, government, and international agencies to contain the epidemic or care for those affected. The forum is funded by a grant from the Research for Health in Humanitarian Crises (R2HC) Programme.

## References

Bofu-Tawamba, N. (2014, November 7). African women face Ebola triple jeopardy. *Al Jazeera America*, Retrieved at

<http://america.aljazeera.com/opinions/2014/11/ebola-response-africanfemalehealthworkersculturecaregivingroles.html>

Mogelson, L. (2015, January 19). When the fever breaks: Government measures have proved inadequate, but communities in Liberia and Sierra Leone are coming up with ways to battle the Ebola Virus. *The New Yorker*. Retrieved at <http://www.newyorker.com/magazine/2015/01/19/when-fever-breaks>

Nina Pham v. Texas Health Resources, Inc. (2015, March 2). (Filed with the District Court of Dallas County, Texas). Retrieved at <http://www.star-telegram.com/news/business/biz-columns-blogs/tarrant-business-blog/article12831470.ece/BINARY/Nina%20Pham%27s%20lawsuit%20v.%20Texas%20Health%20Resources>

The Economist. (2014, November 1). Giving it a shot: Drugmakers bet that vaccines will help in the fight against Ebola. Retrieved at <http://www.economist.com/news/business/21629399-drugmakers-bet-vaccines-will-help-fight-against-ebola-giving-it-shot>

Umaru, F., & Flynn, D. (2014, August 24). Sierra Leone "hero" doctor's death exposes slow Ebola response. *Reuters*. Retrieved at <http://in.reuters.com/article/2014/08/24/health-ebola-khan-idINKBN0GO07C20140824>

## Bios

**Elke Mühlberger** is a renowned expert in the field of BSL-4 hemorrhagic fever viruses. She has a strong research focus on the highly pathogenic filoviruses, Ebola and Marburg virus. Her research interests range from molecular biology studies on filoviral replication and transcription to cellular responses to filovirus infection. Dr. Mühlberger received her PhD in Virology from the Philipps University Marburg, Marburg, Germany in 1993 and continued to work on filoviruses as an independent PI and group leader in Marburg. In 2008, she joined the Department of Microbiology at Boston University, Boston, MA as an Associate Professor and the National Emerging Infectious Diseases Laboratories as the Director of the Biomolecule Production Core.

**Deboleena Roy** is Associate Professor of Women's, Gender, and Sexuality Studies and Neuroscience and Behavioral Biology at Emory University. She received her PhD in reproductive neuroendocrinology and molecular biology from the Institute of Medical Science at the University of Toronto. She is currently Associate Faculty in the Neuroscience Program, Graduate Division of Biological and Biomedical Sciences and Senior Faculty Fellow at the Center for Ethics at Emory University. Her fields of interest include feminist theory, feminist science and technology studies, neuroscience, molecular biology, postcolonial theory, and reproductive justice movements. Her research and scholarship attempt to create a shift from feminist critiques of science to the development of feminist practices that contribute to scientific inquiry in the lab. She has published articles in *Signs: Journal of Women in Culture and Society*; *Hypatia: A Journal of*

*Feminist Philosophy; Neuroethics; Australian Feminist Studies; Rhizomes: Cultural Studies of Emerging Knowledge; Endocrinology; Neuroendocrinology; and the Journal of Biological Chemistry.* She has also contributed to several anthologies including *Handbook for Feminist Research: Theory and Praxis* (2011); *Neurofeminism: Issues at the Intersection of Feminist Theory and Cognitive Science* (2012); *Gendered Neurocultures: Feminist and Queer Perspectives on Current Brain Discourses* (2014); and *Mattering: Feminism, Science, and Materialities* (2016).

**Pamela Scully** is Professor of Women's, Gender, and Sexuality Studies, and Professor of African Studies at Emory University. Her most recent book is *Sara Baartman and the Hottentot Venus: a Ghost Story and a Biography*, co-authored with Clifton Crais (Princeton, 2009, 2010). She is finishing a short biography of President Ellen Johnson Sirleaf of Liberia. She writes generally on sexual violence, transitional justice and feminist theory. She serves on the editorial board of *The Journal of Women's History*, *The Journal of British Studies*, *The Journal of Peacebuilding and Development*, and *Social Dynamics*, and is on the advisory board of *The Journal of Southern African Studies*. Professor Scully works closely with the Institute for Developing Nations, a partnership between Emory University and The Carter Center, which focuses on collaborative research regarding issues of poverty and development.

**Banu Subramaniam** is Professor of Women, Gender, Sexuality Studies at the University of Massachusetts, Amherst. Trained as a plant evolutionary biologist, she seeks to engage the feminist studies of science in the practices of experimental biology. She is author of *Ghost Stories for Darwin: The Science of Variation and the Politics of Diversity* (University of Illinois Press 2014), and coeditor of *Feminist Science Studies: A New Generation* (Routledge, 2001) and *Making Threats: Biofears and Environmental Anxieties* (Rowman and Littlefield, 2005). Spanning the humanities, social, and natural sciences, she works at the intersections of

biology, women's studies, ethnic studies and postcolonial studies. Her current work focuses on the xenophobia and nativism that haunt invasive plant species, and the relationship of science and religious nationalism in India.

**Jennifer Terry** is Associate Professor of Gender & Sexuality Studies at the University of California at Irvine. Her books include *An American Obsession: Science, Medicine, and Homosexuality in Modern Society* (University of Chicago Press, 1999) and two co-edited anthologies, *Deviant Bodies: Critical Perspectives on Difference in Science and Popular Culture* (Indiana University Press, 1995) and *Processed Lives: Gender and Technology in Everyday Life* (Routledge, 1997). She has written articles on reproductive politics, the history of sexual science, contemporary scientific approaches to the sex lives of animals, love of objects, signature injuries of war, and the relationship between war-making practices and entertainment. Her current project is titled *Attachments to War: Violence and the Production of Biomedical Knowledge in 21st-Century America*.