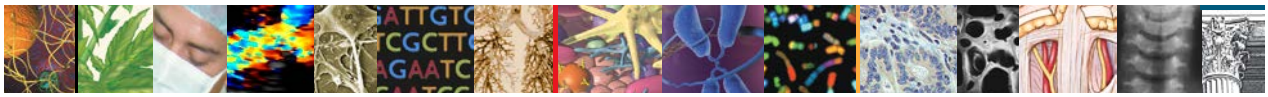

The NEW ENGLAND JOURNAL of MEDICINE

Perspective

Having and Fighting Ebola — Public Health Lessons from a Clinician Turned Patient

Craig Spencer, M.D., M.P.H.

While treating patients with Ebola in Guinea, I kept a journal to record my perceived level of risk of being infected with the deadly virus. A friend who'd volunteered previously had told me that such a journal comforted him when he looked back and saw no serious breach of protocol or significant exposure. On a spreadsheet delineating three levels of risk — minimal, moderate, and high — I'd been able to check off minimal risk every day after caring for patients. Yet on October 23, 2014, I entered Bellevue Hospital as New York City's first Ebola patient.

Though I didn't know it then — I had no television and was too weak to read the news — during the first few days of my hospitalization, I was being vilified in the media even as my liver was failing and my fiancée was quarantined in our apartment. One day, I ate only a cup of fruit — and held it down for less than an hour. I lost 20 lb, was febrile for 2 weeks, and struggled to the bathroom up to a dozen times a day. But these details of my illness are not unique. For months, we've heard how infected West Africans, running high fevers and too weak to move, were dying at the doorsteps of treatment centers. We've seen pictures of dying children crippled by vomiting and diarrhea and unable to drink.

Yet for clinicians, striving and repeatedly failing to cure Ebola is brutal, too. The Ebola treatment center in Guéckédou, Guinea, was the most challenging place I've ever worked. Ebola is frightening not just because of its high fatality rate, but also because of how little we know about it. We cannot explain exactly what it does to our bodies, nor tell patients who survive it how it may affect them in the future. As a clinician and epidemiologist, I've worked in places just miles from active conflict and managed to grow used to the sight of soldiers and the sound of gunfire. But this microscopic virus, an invisible enemy, made me uneasy.

While in Guinea, I often woke up sweating in the middle of the night, my heart racing. I might have felt warm, but my thermometer would read 97.7°F — perhaps it was broken? I started diagnosing myself with gastritis, amebiasis, peptic ulcer disease. Though I understood the connection between psychological stress and physical pain, I'd never experienced it like this. As an emergency physician, I try to approach challenging situations rationally and remain calm under pressure. But my work made it hard for me to relax and feel like myself.

Nevertheless, when I was at the treatment center, I was fueled by

The New England Journal of Medicine
Downloaded from nejm.org on February 27, 2015. For personal use only. No other uses without permission.
Copyright © 2015 Massachusetts Medical Society. All rights reserved.

compassion and the immense challenge of caring for patients with Ebola. I'd never felt so deeply that my decisions could have a measurable impact on other people's lives. Difficult decisions were the norm: for many patients, there were no applicable algorithms or best-practice guidelines. Creating safe discharge plans for pregnant Ebola survivors in their third trimester or advising lactating mothers when it was safe to resume breast-feeding required hours of discussion and planning with colleagues, health promoters, and patients. Every day, I looked forward to putting on the personal protective equipment and entering the treatment center. No matter how exhausted I felt when I woke up, an hour of profuse sweating in the suit and the satisfaction I got from treating ill patients washed away my fear and made me feel new again. Yet I also remember the calm that settled over me the last time I left the center, knowing that I'd no longer be exposed to Ebola. I left Guinea focusing on the socially trying 21 days ahead of me.

Back in New York, the suffering I'd seen, combined with exhaustion, made me feel depressed for the first time in my life. I slept long hours and had a hard time connecting with old friends. I became fearful of the incredibly remote possibility that I could become sick and infect my fiancée, the person I love the most. Touching others and shaking hands — forbidden actions throughout West Africa — still made me uncomfortable. Twice a day, I held my breath in fear when I put a thermometer in my mouth. I did all this worrying well before I ever had a fever or showed any symptoms of Ebola.

The morning of my hospitalization, I woke up knowing something was wrong. I felt different than I had since my return — I was more tired, warm, breathing fast. When I took my temperature and called to report that it was elevated, in some bizarre way I felt almost relieved. Although my worst fear had been realized, having the disease briefly seemed easier than constantly fearing it.

My activities before I was hospitalized were widely reported and highly criticized. People feared riding the subway or going bowling because of me. The whole country soon knew where I like to walk, eat, and unwind. People excoriated me for going out in the city when I was symptomatic, but I hadn't been symptomatic — just sad. I was labeled a fraud, a hipster, and a hero. The truth is I am none of those things. I'm just someone who answered a call for help and was lucky enough to survive.

I understand the fear that gripped the country after I fell ill, because I felt it on a personal level. People fear the unknown, and fear in measured doses can be therapeutic and inform rational responses, but in excess, it fosters poor decision making that can be harmful. After my diagnosis, the media and politicians could have educated the public about Ebola. Instead, they spent hours retracing my steps through New York and debating whether Ebola can be transmitted through a bowling ball. Little attention was devoted to the fact that the science of disease transmission and the experience in previous Ebola outbreaks suggested that it was nearly impossible for me to have transmitted the virus before I had a fever. The media sold hype with flashy headlines — "Ebola: 'The ISIS of Biological Agents?'"; "Nurses in safety gear got Ebola, why wouldn't you?"; "Ebola in the air? A nightmare that could happen"[1-3] — and fabricated stories about my personal life and the threat I posed to public health, abdicating their responsibility for informing public opinion and influencing public policy.

Meanwhile, politicians, caught up in the election season, took advantage of the panic to try to appear presidential instead of supporting a sound, science-based public health response. The governors of New York and New Jersey, followed by others, enacted strict home quarantine rules without sufficiently considering the unintended side effects. The threat of quarantine may cause sick people to defer seeking treatment, and both nationals of affected countries and health care responders returning from those countries may alter their travel plans or misreport their exposure to avoid quarantine. Implementing restrictions that don't accord with the recommendations of the Centers for Disease Control and Prevention[4] also undermines and erodes confidence in our ability to respond cohesively to public health crises. At times of threat to our public health, we need one pragmatic response, not 50 viewpoints that shift with the proximity of the next election. Moreover, if the U.S. public policy response undermined efforts to send more volunteers to West Africa, and thus allowed the outbreak to continue longer than it might have, we would all be culpable.

Instead of being welcomed as respected humanitarians, my U.S. colleagues who have returned

The New England Journal of Medicine
Downloaded from nejm.org on February 27, 2015. For personal use only. No other uses without permission.
Copyright © 2015 Massachusetts Medical Society. All rights reserved.

home from battling Ebola have been treated as pariahs. I believe we send the wrong message by imposing a 21-day waiting period before they can transition from public health hazard to hero. As a society, we recognize the need for some of our best-trained physicians and public health professionals to participate in a potentially fatal mission because failing to stop the epidemic at its source threatens everyone. We should also have faith that these professionals will follow proven, science-based protocols and protect their loved ones by monitoring themselves. It worked for me, and it has worked for hundreds of my colleagues who have returned from this and past Ebola outbreaks without infecting anyone.

For many politicians, the current Ebola epidemic ended on November 4, 2014, the day of midterm elections (and, coincidentally, the day my fever broke). For the U.S. media, it ended a week later, when I walked out of Bellevue Hospital and the country was officially Ebola-free. But the real Ebola epidemic still rages in West Africa. The number of new cases is stabilizing in some areas and declining in others, but more than 23,000 people have been infected,[5] and many are still dying from this disease.

When we look back on this epidemic, I hope we'll recognize that fear caused our initial hesitance to respond — and caused us to respond poorly when we finally did. I know how real the fear of Ebola is, but we need to overcome it. We all lose when we allow irrational fear, fueled in part by prime-time ratings and political expediency, to supersede pragmatic public health preparedness.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

From the Department of Emergency Medicine, Columbia University College of Physicians and Surgeons, New York; and Médecins sans Frontières, Operational Center Brussels, Guéckédou, Guinea.

This article was published on February 25, 2015, at NEJM.org.

1. Cavanaugh T. Weird science: CNN calls Ebola the 'ISIS of bio-agents.' National Review Online. October 6, 2014 (http://www.nationalreview.com/article/389678/weird-science-cnn-calls-ebola-isis-bio-agents-tim-cavanaugh).
2. Nurses in safety gear got Ebola, why wouldn't you? Fox News (Associated Press). October 16, 2014 (http://www.foxnews.com/health/2014/10/16/nurses-in-safety-gear-got-ebola-why-wouldnt).
3. Cohen E. Ebola in the air? A nightmare that could happen. CNN. October 6, 2014 (http://www.cnn.com/2014/09/12/health/ebola-airborne).
4. Centers for Disease Control and Preventions. Interim U.S. guidance for monitoring and movement of persons with potential Ebola virus exposure. December 24, 2014 (http://www.cdc.gov/vhf/ebola/pdf/monitoring-and-movement.pdf).
5. World Health Organization. Ebola situation report. February 18, 2015 (http://apps.who.int/ebola/en/ebola-situation-report/situation-reports/ebola-situation-report-18-february-2015).

DOI: 10.1056/NEJMp1501355

Copyright © 2015 Massachusetts Medical Society.

The New England Journal of Medicine
Downloaded from nejm.org on February 27, 2015. For personal use only. No other uses without permission.
Copyright © 2015 Massachusetts Medical Society. All rights reserved.