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Fear factor: The unseen perils of the Ebola outbreak

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ABSTRACT

As illustrated powerfully by the 2013–2016 Ebola outbreak in western Africa, infectious diseases create fear and psychological reactions. Frequently, fear transforms into action – or inaction – and manifests as “fear-related behaviors” capable of amplifying the spread of disease, impeding life-saving medical care for Ebola-infected persons and patients with other serious medical conditions, increasing psychological distress and disorder, and exacerbating social problems. And as the case of the US micro-outbreak shows, fear of an infectious-disease threat can spread explosively even when an epidemic has little chance of materializing. Authorities must take these realities into account if they hope to reduce the deadly effects of fear during future outbreaks.

KEYWORDS

Ebola; pandemic; fear-related behaviors

By late 2014, about a year into the largest, longest, and deadliest Ebola outbreak since the disease was first identified nearly four decades earlier (Shultz et al. 2016a), healthcare workers in western Africa had become so concerned about deaths occurring in homes that a US response team in Liberia requested a “rapid anthropological assessment” of the phenomenon from their higher-ups at the Centers for Disease Control and Prevention. The resulting study included one particularly revealing finding: In a one-month period that year, 30 percent of “the 60–90 deceased persons collected weekly” by the Liberian Red Cross tested positive for the Ebola virus, and “nearly half of those had been collected in homes.” To put this in perspective, the report noted that Ebola home deaths should not be occurring at all (Allen and Lacson 2015). Because the Ebola virus is so easily transmitted by contact with the bodily fluids of an infected person, home care is not only potentially deadly for those treating the victim but extremely dangerous in terms of the overall spread of the disease in a community. In the face of these grim facts, most outsiders probably have trouble understanding why more victims did not make it to the special treatment units set up by healthcare workers. Yet, fear has a way of stymieing rational behavior, and home deaths are just one of the symptoms of the deeper invisible barriers confronting those trying to contain epidemics and treat the afflicted.

It was indeed a momentous occasion when the World Health Organization announced the official end of the Ebola outbreak as a “public health

emergency of international concern,” in March 2016, but it marked the end of a horrific few years that claimed 11,323 lives – almost 40 percent of the 28,646 people infected (WHO 2016). Looking back, we can now see that fear-related behaviors were not only a major driver of this epic crisis, triggering cascades of new infections (Shultz, Baingana, and Neria 2015; Shultz et al. 2016a), but also, among other things, increased psychological distress and hindered the timely treatment of Ebola-infected persons and patients with other serious medical conditions, such as malaria, HIV, and tuberculosis. And as the case of the US micro-outbreak shows, fear had a powerful effect beyond the epicenter nations of Guinea, Sierra Leone, and Liberia – even when there was little actual threat. During future epidemics, a better understanding of how these fear-related behaviors affect individuals and groups could easily prove to be just as essential as life-saving medical treatment.

Fear and fear-related behaviors

As an emotional and physiological reaction, the experience of fear can be extremely uncomfortable, distressing, and disconcerting. When fear transforms into action, the behaviors it spawns manifest publicly and can spread rapidly and contagiously, in an epidemic fashion. These fear-related behaviors can be an individual or collective response to a perceived threat or to an actual exposure to a potentially traumatizing event. These behaviors are rarely founded on clear reasoning

or accurate perception of risks, yet they can shape events powerfully and coalesce into the collective actions of families, social groups, and entire neighborhoods.

From a scientific standpoint, reactions to fear are normal and potentially beneficial, and given the nature of Ebola, fear of the disease during the 2013–2016 outbreak was understandable, not to mention almost universal. The Ebola virus is undetectable to the human senses and no disease symptoms appear for days following infection. These stealthy traits evoke fear and dread, as do the fearsome symptoms of the disease when they eventually appear.¹ Some early public-health campaigns, with stark messages like “Ebola Kills” and unnerving visuals of things like fanged fruit bats (one of the mammalian carriers of the virus), contributed to public fear as well. Those who did make it to proper care facilities experienced suffering and death in close proximity, isolated from supportive family members, their only human contact coming in the form of healthcare workers covered in special protective gear.

Furthermore, some fear-related behaviors were based on myths and misconceptions, primarily related to modes of transmission (e.g. Ebola was transmitted through the air, or spread as part of an international conspiracy, or appeared following the crash of a mysterious “witch plane” [WHO 2014]). Other myths involved prevention (bathing with salt and hot water prevents infection and illness) and treatment (traditional healers can cure Ebola; healthcare workers harm rather than heal patients in treatment centers) (Ogoina 2015; Allen and Lacson 2015; Focus 1000, Centers for Disease Control and Prevention, and UNICEF 2014).

In addition to fear, epidemics – which become pandemics when they cross borders and spread throughout whole regions, as the Ebola epidemic did – can also trigger serious psychosocial consequences, which fear can then exacerbate. These derive from experiences of trauma, loss, and change (Shultz et al. 2016b) and include individual psychological consequences like stress, grief, and mental disorders. Also included are social consequences like stigma and discrimination, the interruption social networks, and severe shortages of basic necessities (CDC 2016). Such trauma might take the form of seeing others die or fearing death oneself, especially if infected. But, during the Ebola outbreak, people experienced trauma in other forms, as well, such as the re-traumatizing experience of reliving the harsh realities of mass fatalities, regional instability, and community violence in nations that were still grappling with the psychological aftermath of barbaric civil wars

(Faherty and Doubeni 2015). Larger changes occurring in communities – from discrimination against survivors to movement restrictions, curfews, and quarantines – contributed to the psychosocial impact as well.²

Fear and the spread of Ebola

One of the most devastating consequences of fear-related behaviors during the Ebola outbreak was the decision of infected persons to avoid treatment centers in favor of home care, which inevitably accelerated the spread of the disease. By remaining in the community, they decreased their personal chances for survival, while also increasing their encounters with others, who were then more susceptible to infection. There were also reports that a number of admitted patients, after witnessing suffering around them, fled from the treatment units, carrying the disease back into the community (Shultz, Baingana, and Neria 2015).

More common, family members of persons with Ebola symptoms fearfully sequestered their ill relatives out of sight in their homes rather than admit them to newly erected treatment centers. Abject fear of these facilities was understandable. Outsiders saw Ebola patients enter but only a fraction reemerged alive. Meanwhile, a steady stream of body bags exited the premises and relatives were prohibited from reclaiming the corpses. Failure to communicate with family members regarding the operations of the treatment centers contributed to the fear.

The alternative option, secretly caring for symptomatic patients in home settings without proper protective equipment – a powerful and prevalent example of fear-related behavior – frequently resulted in multiple cases developing within a given household. There were also many instances when religious leaders, traditional healers, and family members continued to practice the hands-on body-cleansing rituals and burial practices for persons who had succumbed to Ebola. Because corpses of Ebola victims remain highly infectious, many new cases developed in this manner. There were also instances in which healthcare workers treated Ebola patients in their homes or in private clinics without proper protection and did not refer these patients to isolation units or treatment centers.

By late 2014, the problem of home deaths spurred the US Centers for Disease Control to launch its “rapid anthropological assessment” of the phenomenon. After conducting a series of focus groups and key informant interviews, the rapid response team identified a litany of factors associated with delayed care-seeking and home deaths, including concerns about quality of care in treatment centers, lack of information about these

units, strong opposition to cremation, concerns about Ebola stigma, fear of household quarantine, fear about lack of food for the family while under quarantine restrictions, and limited access to health services for non-Ebola illnesses. As a testament to the prominence of fear-related behaviors, the team acknowledged that “decisions about whether or not to seek health care or report a loved one’s death” were taken amid “fears and distrust” of public health response efforts, contributing to the incidence of home deaths in the Liberian county being surveyed (Allen and Lacson 2015).

Fear as an impediment to treatment

On the other side of the equation, fear also affected the medical treatment that was offered. Hundreds of healthcare workers provided care tirelessly and risked their lives in the process, particularly in the early months when protective gear was in short supply and protocols for proper use of the equipment had not been taught. Many health professionals became afflicted with the Ebola disease themselves, and 58 percent of them died, a rate that was 50 percent higher than for patients from the general population. This altruistic behavior was a display of heroism in the face of extreme risk and emphatically *not* an illustration of a fear-based reaction to the outbreak.

However, fear-related behaviors did play a prominent role in decreasing access to life-saving care. Some healthcare workers opted to vacate their professional roles rather than risk personal illness, death, and possible transmission to family members. Given the circumstances, this should not have been surprising: Research has shown that healthcare workers are especially concerned about working during virulent infectious disease outbreaks, and some indicate they will abandon their profession (Barnett et al. 2009; Hope et al. 2010). During the 2013–2016 Ebola outbreak, there were instances where health workers refused to work or took extended sick leave. A number of international nongovernmental organizations also preemptively withdrew their healthcare personnel from working in high-risk settings, causing some health facilities to temporarily shutter when they were needed most.

Fear-related behaviors took more insidious forms as well. Misinformation and misperceptions led to blaming healthcare workers for bringing the epidemic and harming patients at treatment centers. Violent, sometimes fatal attacks were perpetrated against health workers and humanitarian personnel. Healthcare workers and their family members were sometimes stigmatized and shunned. The stigma even reached developed countries, where draconian restrictions

were placed on medical professionals who were willing to volunteer vacation time to serve in western Africa only to return home to extended mandatory quarantines. This occurred during a time of acute staff shortages in the region, when international volunteer medical personnel were greatly needed.

Fear and its ripple effects

Fear not only accelerated the spread of Ebola and impeded treatment, but it also caused other serious problems as well, hampering the treatment of non-Ebola patients and harming the mental health of individuals and communities.

The fear-fueled urgency of treating Ebola had the effect of rerouting healthcare personnel and repurposing facilities away from the care of persons with treatable, non-Ebola illnesses. On top of that, not only did the demands of treating Ebola severely diminish the healthcare system’s capacity, but fear-related behaviors caused citizens with these treatable ailments to forego medical care due to fears of contracting Ebola. The consequences were devastating. An estimated 10,600 preventable deaths occurred from untreated or inadequately treated cases of malaria, tuberculosis, and HIV – almost equivalent to the 11,323 total deaths from Ebola itself (Parpia et al. 2016). Meanwhile, both infant mortality and maternal mortality increased as hospital and professional-attended deliveries declined sharply (Iyengar et al. 2015), and a total of 17,300 children lost one or both parents to the disease (CDC 2016). In some instances, these orphans were abandoned and not cared for in their communities, an obvious threat to their psychological well-being.

Fear-related behaviors also put certain subgroups – such as Ebola survivors and their households, families of the deceased, burial teams, and healthcare and humanitarian-aid workers – at increased risk for mental disorders.

Ebola survivors seemed to be especially at psychological risk. This outbreak was notable for having the most cases and deaths but also the most survivors – more than 17,300 (Shultz et al. 2016a). Based on the widely held belief that survivors remained infectious and capable of spreading disease, many survivors were shunned and barred from returning to their workplaces, and some were physically assaulted. Stigma and discrimination also extended to the family members and households of Ebola survivors.

These behaviors were particularly ironic since survivors are generally immune from recurrence of the disease (apart from some rare transmission risks). As part of a community-engagement strategy, some survivors

were placed in treatment centers as social mobilizers. This was not without a downside, however. On-scene mental health professionals noted that Ebola survivors who were recruited to work in treatment units were not adequately assessed regarding their abilities to re-enter the “hot zones” – where they had previously received care – without being traumatized. Guidelines needed to be developed for treatment-unit employers to assess physical and mental fitness, and educational readiness, prior to hiring survivors. Better infection-control education was also needed to diminish the risks of survivors who worked in treatment centers becoming vectors of transmission to their family members if they were lax in the application of infection-control procedures due to their own immunity.

Ripple effects touched larger communities as well

Authorities enacted a number of measures to reduce the risks of intermingling infected and non-infected persons. Some policies were public-health measures but others were more heavy-handed movement restrictions. These included nighttime curfews, community quarantines, lockdowns, and house-to-house searches for infected individuals. In the midst of a raging pandemic disease, the enforcement of such harsh restrictions had the effect of constraining the populace to remain in areas where disease was spreading aggressively. Such constrictions of civil liberties fostered the expression of fear-related behaviors.

At the international level, precautionary health measures, such as indiscriminate screening of West Africans residing in the United States, led to stigmatization (Faherty and Doubeni 2015). Shame, discrimination, and stigma, all of which are well known risk factors for psychological distress and common mental disorders, were downstream consequences of the strict, and frequently irrational, security measures implemented to curb the Ebola pandemic globally.

Heaped upon the fear dynamics that were so tangible in Ebola-affected communities, the national and international responses added layers of stigma. Countries adjacent to the intensive transmission nations closed their borders. Visa restrictions and travel bans were enacted even by nations such as Canada that never saw an Ebola case. Half of the international flights to and from the “intense transmission” nations in western Africa were suspended. Individuals traveling abroad from the region faced discrimination. International commerce faltered, as goods and services from the epicenter nations lost their value; Guinea, Sierra Leone, and Liberia all experienced plummeting downturns in their respective GDPs.

Fear in the absence of disease: the US micro-outbreak

As impressive as the effects of fear proved during the pandemic in western Africa, it's especially fascinating to consider how powerful they were in the United States, where only four cases occurred, posing only a minuscule public-health threat.

In October 2014, at the very moment when the Ebola outbreak was peaking in western Africa, four cases were diagnosed in the United States within one month (Shultz, Baingana, and Neria 2015). The first case identified, Thomas Duncan, was a Liberian national who became infected in his home country, traveled to the United States while asymptomatic, and developed Ebola disease symptoms while in Dallas, Texas. He was initially evaluated and discharged from Texas Presbyterian Hospital but was later admitted when he returned with worsening symptoms. He died during his inpatient stay, and two nurses who cared for him at his bedside became infected and later developed Ebola themselves.

The outbreak was noteworthy for three firsts: the first Ebola case to enter the United States undetected with symptom onset occurring while inside the country, the first two direct-contact transmission cases occurring within the United States, and the first two Ebola cases (the same two cases) occurring in health-care workers infected in the line of duty. The fourth US case was a New York physician who sustained an Ebola infection in western Africa while providing volunteer medical assistance. Symptom onset occurred several days after his return to America.

Despite the microscopic scale of the US outbreak, the fear response throughout the country was extraordinary in its breadth and magnitude.

Confirmation that Ebola infection had occurred in a US hospital immediately jolted all healthcare systems nationwide into high alert mode. No one wanted to be “the next Texas Presbyterian.” The broadcast media lit up with a crossfire of accusations. The director of the Centers for Disease Control and Prevention declared that there must have been a “breach in protocol,” yet the center subsequently revised and reissued its own protocol on personal protective gear five times over the ensuing months. The nursing union rallied and blamed the Texas hospital for failing to properly train and protect its staff. The hospital blamed “interoperability” issues with electronic health records for allowing Thomas Duncan to be discharged while infected and symptomatic. A Texas senator elevated blame to the federal level for having permitted air travel from “infected countries” to the United States. Later, the

nurses who developed Ebola sued the Texas healthcare system.

This four-case scenario provided a powerful and supremely expensive wake-up call to upgrade healthcare system preparedness.³ It also provided a fascinating case study in the disproportionate power of fear in the absence of any realistic public-health threat.

The Ebola saga surged to the top of TV news lineups throughout October 2014. There were millions of Ebola Tweets (Lee 2015) and a massive spike in Google searches. Sherry Towers and her colleagues performed elaborate mathematical analyses showing how Ebola news stories propelled a “contagion” of Google searches and Tweets (Towers et al. 2015). Most impactful psychologically was the indirect exposure of the US population to a very high dose of fear-laden reporting, with many news accounts intimating that the general public was at grave risk. This was borne out in November 2014 polls showing that Ebola was the third-most urgent health concern for the American public – after healthcare cost and access, and, amazingly, ahead of all other diseases – and that the public had very little confidence in public-health messaging (SteelFisher, Blendon, and Lasala-Blanco 2015). Fear was further propelled as news outlets widely publicized estimates that the global pandemic was soaring toward one million cases by the end of the year, based on woeful modeling techniques.

Any Americans who sat through media broadcasts experienced intensive indirect exposure to a distorted portrayal of transmission risks. Fear-driven media messaging is not neutral in its effects; well-designed studies have demonstrated that indirect exposure to traumatic events through media alone can elevate population risks for distress and even for development of acute stress and short-term post-traumatic stress symptoms (Neria and Sullivan 2011; Holman, Garfin, and Silver 2013). In tandem with the constant media fusillade, multiple surveys conducted by news and media organizations in the United States documented widespread public fear compounded by strongly held beliefs in personal and national vulnerability to this deadly disease (Dennis and Craighill 2014).

On balance, of course, the country experienced a brief, four-case, one-month Ebola “blip” that, at the very most, placed several hundred citizens – of nearly 319 million – momentarily within direct contact range of these infected individuals. Yet, by the end of October that year, 65 percent of the American public expressed fears of Ebola sweeping throughout the country (Dennis and Craighill 2014). Such is the power of fear propagation even when decoupled from any actual risk of disease transmission.

Learning from Ebola

All told, life-saving lessons from prior epidemics were somehow not readily applied during the 2013–2016 Ebola outbreak, even though they could have saved lives. Lessons learned in real time during the outbreak were not efficiently disseminated, either, leading to preventable cases of disease and loss of life.

During an outbreak, fear-related behaviors have the potential to accelerate the spread of a disease, diminish access to life-saving interventions, intensify psychological distress, and compound psychosocial consequences. During future epidemics, authorities must undertake to do far more to reduce the destructive effects of these behaviors, such as channeling fear into more productive behavior, working with news media to shape responsible reporting, and perhaps most important, working with medical anthropologists and local public-health leadership to assess the cultural dimensions of an outbreak and define the “lived experience” of those affected. These last improvements especially would enhance public trust and ensure that intervention methods are acceptable to the community and that information about risks is based on facts rather than fiction. If officials do not take steps like these seriously, however, fear will continue to make epidemics even more deadly.

Notes

1. Ebola is legendary for the popularized accounts of gruesome hemorrhagic symptoms including patients “bleeding out” at the time of death. Although the hemorrhagic manifestations were somewhat less common in the 2013–2016 outbreak – about 18 percent of cases, according to the Centers for Disease Control and Prevention (see <http://www.cdc.gov/vhf/ebola/healthcare-us/preparing/clinicians.html>) – all of the thousands of persons who were diagnosed with the Ebola disease experienced an extended, life-threatening illness with some combination of pain, discomfort, and debility that can persist for years.
2. For a concise catalog of the psychosocial consequences of the 2013–2016 Ebola outbreak, see Van Bortel et al. (2016).
3. The US federal government allocated \$2.4 billion to Ebola response, including \$798 million directed to the Centers for Disease Control and Prevention to focus on nationwide healthcare system training, stockpiling of protective gear, and system upgrades for pandemic diseases.

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Notes on contributors

James M. Shultz is the director of the Center for Disaster and Extreme Event Preparedness at the University of Miami's Miller School of Medicine.

Benjamin M. Althouse is a research scientist at the Institute for Disease Modeling, in Bellevue, Washington, and an affiliate assistant professor at the University of Washington's Information School, in Seattle, Washington.

Florence Baingana is a research fellow at Makerere University's School of Public Health, in Kampala, Uganda.

Janice L. Cooper heads the Carter Center's Liberia Mental Health Program, in Monrovia, Liberia.

Maria Espinola is an assistant professor of clinical psychiatry in the Department of Psychiatry and Behavioral Neuroscience at the University of Cincinnati's College of Medicine.

M. Claire Greene is a Drug Dependence Epidemiology Training Fellow at Johns Hopkins Bloomberg School of Public Health.

Zelde Espinel is a chief psychiatry resident in the Department of Psychiatry and Behavioral Health at the University of Miami's Miller School of Medicine.

Clyde B. McCoy is the director of the Comprehensive Drug Research Center at the University of Miami's Miller School of Medicine.

Laurie Mazurik is an emergency physician at Sunnybrook Health Sciences Centre, in Toronto, and the project leader for the Ebola Web Collaborative.

Andreas Rechkemmer is a professor and the American Humane Endowed Chair at the Graduate School of Social Work at the University of Denver.

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