

# The Role of Fear-Related Behaviors in the 2013–2016 West Africa Ebola Virus Disease Outbreak

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**Abstract** The 2013–2016 West Africa Ebola virus disease pandemic was the largest, longest, deadliest, and most geographically expansive outbreak in the 40-year interval since Ebola was first identified. Fear-related behaviors played an important role in shaping the outbreak. Fear-related behaviors are defined as "individual or collective behaviors and actions

initiated in response to fear reactions that are triggered by a perceived threat or actual exposure to a potentially traumatizing event. FRBs modify the future risk of harm." This review examines how fear-related behaviors were implicated in (1) accelerating the spread of Ebola, (2) impeding the utilization of life-saving Ebola treatment, (3) curtailing the availability of

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medical services for treatable conditions, (4) increasing the risks for new-onset psychological distress and psychiatric disorders, and (5) amplifying the downstream cascades of social problems. Fear-related behaviors are identified for each of these outcomes. Particularly notable are behaviors such as treating Ebola patients in home or private clinic settings, the "laying of hands" on Ebola-infected individuals to perform faith-based healing, observing hands-on funeral and burial customs, foregoing available life-saving treatment, and stigmatizing Ebola survivors and health professionals. Future directions include modeling the onset, operation, and perpetuation of fear-related behaviors and devising strategies to redirect behavioral responses to mass threats in a manner that reduces risks and promotes resilience.

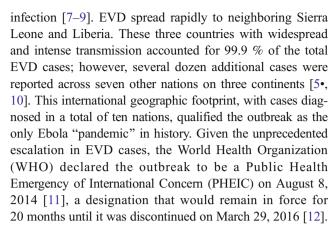
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#### Introduction

The 2013–2016 West Africa Ebola virus disease (EVD) outbreak set off two intermingled and interacting epidemic processes: disease transmission and fear propagation [1••, 2•, 3, 4•]. The focus of this review is on the crossroads linking fearrelated behaviors (FRBs) to disease spread and downstream consequences. FRBs are defined as "individual or collective behaviors and actions initiated in response to fear reactions that are triggered by a perceived threat or actual exposure to a potentially traumatizing event. FRBs modify the future risk of harm" [2•, 3].

As context, the 2013–2016 EVD epidemic transcended all 24 preceding outbreaks that occurred in the 40-year interval since Ebola was first recognized in 1976 [5•, 6]. Epidemiologists determined that the trigger event was the zoonotic infection of a small child in rural Guinea in December 2013, setting off multiple extended chains of

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During the 28-month duration of the outbreak, a cumulative total of 28,652 Ebola cases were diagnosed and 11,325 died from the disease, yielding a case-fatality rate of 39.5 %. More than 17,300 EVD patients survived. To place the pandemic in perspective, when comparing data for the 2013–2016 outbreak to the combined totals for all 24 previous EVD episodes, there were 12 times more cases, seven times more deaths, and 21 times more EVD patients who recovered from their illness [5•].

This paper provides a conceptual overview of Ebola fears and FRBs followed by a presentation of the prominent FRBs at play during the pandemic. FRBs are organized in relation to their primary influences on Ebola risks and epidemic dynamics: accelerating the spread of EVD, impeding the utilization of life-saving EVD treatment, curtailing the availability of medical services for treatable conditions, increasing the risks for new-onset psychological distress and psychiatric disorders, and amplifying the downstream cascades of social and societal issues [2•, 3].

This review was conducted by a multidisciplinary author team composed of professionals from the fields of psychiatry, psychology, medical anthropology, global health, mental health, public health, and infectious disease modeling. Together, these professionals are exploring the role of FRBs in complex health emergencies and situations of mass threat.

### Overview of Fear and Fear-Related Behaviors

### Fear and Ebola

According to Morens, Folkers, and Fauci, "emerging infections remain among the principal challenges to human survival" [13]. Perhaps intensified by this existential threat, communicable diseases have a special propensity to arouse fear because infection is 'transmissible, imminent, and invisible" [14•]. Irrespective of fear, a life-threatening illness typically produces psychological consequences, but the simultaneous experience of fear creates a powerful and distressing overlay [15].



Stress and fear reactions in response to infectious disease are considered normal and potentially adaptive or protective [16]. Specific to EVD illness and death, fear is expected and has been documented internationally throughout the history of EVD outbreaks [17, 18, 19•, 20–22, 23•, 24•]. During the 2013–2016 EVD outbreak, fear was understandable, reality-based, and almost universal [24•].

Fear-Arousing Aspects of the Disease Agent and Mammalian Reservoir

Viral microbial agents, including the Ebola virus, are undetectable to the human senses and no disease symptoms appear for days following infection. The invisible-colorless-odorless-submicroscopic properties of a viral agent create anxious uncertainty regarding risk, exposure, and infection that sometimes escalates to intense fear and dread [21, 25].

Artistic depictions of the Ebola virus exaggerate its stubby snake-like appearance [26]. Equally fearsome are the photos of the virus' most recognized mammalian "reservoir," the fruit bat, showing the creature hanging inverted with wings spread and fangs menacing. Some of the early public health campaigns, with frightening visuals (depicting end-stage EVD), scary messages ("Ebola Kills"), and pessimistic pronouncements (there is no cure) may have engendered, rather than mitigated, public fear.

### Fear-Arousing Disease Symptoms

Following onset of symptoms, the acute Ebola disease process is physically anguishing and profoundly debilitating. For those who survive, the recovery process is protracted. Ebola is particularly renowned for its hemorrhagic manifestations that presented in about 18 % of patients during the 2013–2016 EVD outbreak [27]. As patients struggled through a constellation of physically distressing symptoms, they were aware that they were very likely to die.

### Fear-Arousing Aspects of the Care Environment

The traditional environment of care characterized by traditional healers, communal rituals, body manipulations, and cultural treatment techniques was invalidated [28•]. With the arrival of the foreign health professionals and the operationalization of Ebola treatment units (ETUs), the usual settings of care were replaced by sanitized spaces and communal care wards with different sets of rules for treatment and care. Patients were denied traditional ritualistic practices.

The Ebola treatment centers did not provide privacy, so those afflicted with EVD directly witnessed other patients (sometimes their own loved ones and children) in close proximity who were displaying the full spectrum of EVD symptoms, and sometimes "bleeding out" and dying, with the corpse remaining in view for hours [29••].

Patients were treated under strict infection control precautions. Medical personnel were completely cloaked in protective suits, presenting a disturbing sight that underscored the patient's highly infectious state and precarious existence [14•]. Adding to the stress of battling a life-threatening ailment, patients were necessarily denied bedside social support from family members. In the era of EVD, the usual interpersonal contact and the proximity with relatives, social behaviors that are otherwise instrumental to the healing process, were transmuted into deadly Ebola risk behaviors [30].

### Fear-Arousing Elements of Governmental Response

Compounding these fears were government attempts to stop the spread of Ebola through emergency declarations, the closing of schools and nonessential businesses, quarantine measures that were sometimes militaristic in style, house-to-house searches for EVD cases, and community lockdowns. Some government measures designed to mitigate disease transmission such as banning "mass gatherings," curtailing social interactions, and repurposing public facilities (e.g., using a school as a holding center for suspected and probable EVD cases), actually backfired, generating fear reactions and FRBs that increased risks [31].

#### Fear and Fear-Related Behaviors

Steimer [32] defines fear as "a motivational state aroused by specific stimuli that give rise to defensive behavior or escape." Fear is a defining expression of the acute stress response, detectable physiologically and sensed palpably by the individual.

The experience of fear is magnified when the traditional sociocultural references of the collective and the individual, such as the cultural etiology of diseases and the traditional approaches to disease control and treatment, collapse or become invalidated [33–35].

When fear, the "motivational state," transforms into actions, individual fear behaviors manifest at the aggregate level and may spread rapidly and contagiously, in epidemic fashion, among groups of persons who share the fear and observe the behaviors of each other. This may trigger an exponential trajectory of fear cascades in the larger public realm. The behavioral manifestations of the stress response, in which fear plays a prominent role, have been described as the "fight or flight" response [16], or more inclusively, as the "freeze, flight, fight, fright, faint" behavioral repertoire [36].

For this review, we provide the following definition: "Fear-related behaviors (FRBs) are individual or collective behaviors and actions initiated in response to fear reactions that are triggered by a perceived threat or actual exposure to a potentially traumatizing event. Importantly, FRBs modulate the future risk of harm" [2•, 3].



Fear is instrumental for human species survival. Ideally, fear would motivate effective, protective actions. The sequence would go something like this: a perceived threat and/or traumatic exposure produces a thought (e.g., I am at risk of being infected with Ebola) that elicits a negative emotional reaction (e.g., fear of the Ebola agent, disease, and death) that stimulates behavioral responses intended to counteract the fear and, more importantly, mitigate the threat. The reality during the 2013–2016 Ebola outbreak is that FRBs did not operate in such a rational, logical, or preventive manner for at least six reasons:

- 1. Fear and stress interfere with cognitive processing.
- Personal assessment of risk is hampered by lack of information.
- Individuals' risk assessments are poor even with good information.
- Individual actions are influenced by the actions of other individuals.
- 5. Mass actions are influenced by the actions of the masses.
- 6. Fear-driven actions may escalate and reach a tipping point when compounded by a collapse of the individual's or the community's values and cultural references, and/or an erosion of systems of governance and public order.

It was not possible to estimate the numbers of persons who took constructive actions, titrating fear in a manner that kept them safe and free from infection. Clearly, many people in the face of substantial fears contributed to mitigating the spread of the outbreak. What was more observable was the reverse, the degree to which FRBs created negative, risk-elevating consequences.

# Fear-Related Behaviors in the 2013–2106 EVD Outbreak

This review will examine how FRBs (1) accelerated the spread of EVD, (2) impeded the utilization of life-saving EVD treatment, (3) curtailed the availability of medical services for treatable conditions, (4) increased the risks for new-onset psychological distress and psychiatric disorders, and (5) amplified cascade-like downstream phenomenon such as stigma and discrimination, as well as social and societal issues.

### FRBs Accelerated the Spread of Ebola Virus and EVD

FRBs that accelerated the spread of Ebola virus and EVD:

FRB1: Providing Ebola care in home settings

FRB2: Conducting unsafe body cleansing and burial practices

FRB3: Fleeing from home communities/migrating to new settings



Fundamentally, three elements are required to trigger and sustain an infectious disease outbreak: (1) settings that facilitate contact between infected and noninfected persons, (2) specific behaviors that transmit the disease agent, and (3) a larger enabling social and societal environment.

Regarding settings, during the early months of the 2013–2016 outbreak, an international team of disease modelers estimated that "38.3 percent of infections were acquired in hospitals, 30.7 percent in households, and 8.9 percent while participating in funerals" [37].

Regarding behaviors, movement of a disease agent from a source of infection to a susceptible host is the basis for transmitting communicable diseases [5•]. Ebola spreads by direct contact. In a study of 937 household contacts of 151 EVD survivors, 448 (48 %) became ill with EVD. Investigators demonstrated a hierarchy of risk exposures for acquiring Ebola infection. Eighty-three percent of those who handled a corpse became infected as did 61 % of those who directly handled bodily fluids, 49 % with history of direct "wet" contact, 38 % with direct "dry" contact, 26 % with indirect "wet" contact, and 11 % with indirect "dry" contact [38••]. This study provides definitive evidence demonstrating how risk behaviors inherent in home care (FRB1) and burial practices (FRB2) translated into Ebola virus infection and EVD illness [38••].

Regarding the larger enabling environment, all three highly affected countries are characterized by least developed nation status, high poverty rates, and largely ineffective governance systems.

### FRB1: Providing Ebola Care in Home Settings

Fearful of seeking care in the Ebola treatment centers, many families cared for active EVD cases in their homes secretly, without notifying health authorities. This highly prevalent FRB continued even after information circulated about the elevated risk for Ebola infection for in-home caregivers and other household members [1••, 19•, 39••].

Caregiving in the home, in lieu of seeking care in the ETUs, was one of the primary FRBs identified as driving the spread of Ebola and decreasing the chances of survival, leading to in-home death and burial risks [38••, 39••]. Providing in-home care produced numerous case clusters, beginning at the household level and frequently extending into the community as elongating chains of serial infections.

A CDC medical anthropology team surveyed family members in Liberia who made the choice to care for ill loved ones in the home [39••]. Their findings provided strong evidence that fear was a primary motivator for this consequential decision. Study participants chose to harbor their ill loved ones at home rather than take their chances with the ETUs. This choice was founded on fears that derived from personal and community experiences: some of their loved ones who entered

the ETUs never returned; other family members did not receive quality care; information about the patient's status was rarely provided and seldom in a timely fashion; apparently well family members were traced for weeks as "contacts" of the EVD patient; and the act of spraying patients with chlorine and chemicals aroused fear [39••]. According to key informant interviews, many local residents believed that staff working in the ETUs were actually harming or killing the patients [39••].

Home-based Ebola care also contributed to anomalies observed in the epidemic patterns. These included explosive "flare-ups" in regions that had seemingly achieved disease control and unexpected "hidden caseloads" suddenly appearing when new treatment facilities opened [40].

In some areas, in-home care was also prompted by necessity. The severe shortage of health workers, coupled with long lines at ETUs at the height of the epidemic when bed capacity was low, thrust family members into the role of primary caregivers for their sick loved ones, thereby elevating their own infection risks as they provided support at the bedside with limited means of self-protection.

FRB2: Conducting Unsafe Body Cleansing and Burial Practices for the Deceased

More than 11,000 EVD patients died during the outbreak. A substantial proportion died in home settings where the case-fatality rate was higher than in ETUs. Many who died displayed hemorrhagic symptoms during the final stages of illness [5•].

Once these Ebola victims died, their corpses, bedding, and utensils remained highly infectious and hazardous for anyone who handled them without proper protection. Yet when a relative died at home, it was common for grieving family members to conduct the respectful rituals of cleansing and preparing the body of the deceased [1••, 19•, 38••, 39••, 41, 42•]. Customs involving direct touch (e.g., the laying of hands to "cure through faith," hands-on burial preparations) were strongly implicated in Ebola virus transmission [1••, 8, 19•, 38••, 39••, 41, 42•, 43–47]. Traditional healers and religious leaders continued to promote these practices and people were fearful for the fate of their deceased loved one if the practices were not faithfully followed.

Psychological distress was associated with imposed policies that restricted the observance of burial customs that involved direct contact with the body of the deceased. In the interest of halting the epidemic, trained burial teams frequently took over the body-handling duties. Family members were not permitted to grieve their losses according to custom. Additionally, the tradition of treating patients or burying the deceased in ancestral lands was curtailed due to bans on transporting infected or dead bodies across borders [47].

Funeral traditions carry a high risk for Ebola virus transmission [48, 49]. In rural Sierra Leone, the corpse is washed

by relatives of the same gender. Often this involves persons of different lineages who reside in other villages. In some communities, when a husband died, the wife's head was shaved and anointed with mud formed from the washings of the cadaver, a custom "that frees her from the attentions of the dead husband's jealous spirit, and prepares her to be remarried to one of his brothers, or to return to her own family" [50]. The hands-on preparation of a highly infectious corpse frequently resulted in new infections through direct transfer of Ebola virus to noninfected individuals [38••].

Another clash between cultural traditions, religious beliefs, and epidemic control procedures occurred in locales where the decision was made for trained teams to retrieve and cremate the bodies of Ebola victims. There was strong opposition to "burning the bodies," motivating some families to perform clandestine burials. CDC medical anthropologists noted three primary reasons for conducting "secret burials": fear of stigma, fear of having the family placed in quarantine, and fear of cremation [39••].

**Notes from the Field** Particularly on point for the discussion of FRB1 and FRB2 are observations made by CDC medical anthropologists [39••]. Their research was guided by this premise: "Ebola Virus Disease (EVD) home deaths occur as the result of infected persons not being detected early and sent to Ebola Treatment Units (ETUs) where they can access care and have an improved chance of survival. From a public health standpoint, EVD deaths should not occur at home" [39••].

Their qualitative analyses uncovered a litany of factors associated with delayed care-seeking and home deaths: (1) concerns about quality of care in ETUs, (2) lack of information about the ETUs, (3) strong opposition to cremation, (4) concerns about Ebola stigma, (5) fear of household quarantine, (6) fear about lack of food for the family while under quarantine restrictions, and (7) limited access to health services for non-Ebola conditions. As a testament to the prominence of FRBs, the team concluded, "...decisions about whether or not to seek health care or report a loved one's death take place in a context in which the *circulation of community and first-person narratives about EVD fears*, and distrust of its medical/public health response efforts, ... contributed to the occurrence of EVD-related home deaths."

FRB3: Fleeing From High-Incidence Communities/Migrating to New Settings

Migration based on fear qualifies as an FRB. Several explanations were ascertained for why individuals left high-incidence communities, including (1) fear of infection and illness, (2) fear of stigma that branded communities with a high concentration of EVD cases, and (3) fear of conflicts inherent in being asked to inform on ill neighbors [39••].



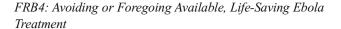
At face value, choosing to leave a community with a high rate of Ebola virus infection seems like a rational, risk-reducing "flight" option. Counterintuitively, during the 2013-2016 outbreak, fleeing actually increased Ebola disease spread and EVD mortality for four reasons. First, in some instances, the ill were left behind, abandoned without care or support, thus diminishing their chances for survival [39...]. Second, some persons with acute illness chose to flee due to fear of being identified and transported to an ETU. These persons were infectious and invariably placed anyone with whom they traveled or lodged at high risk. Third, quite insidiously, population movements included an admixture primarily made up of persons who were well but with an occasional infected individual who started the journey asymptomatic while incubating the virus. These migrating groups unwittingly brought Ebola infection with them. Even as they attempted to escape from disease and stigma, these groups became vectors of infection, sometimes introducing EVD into new regions based on their movements. Ladner and colleagues conducted sophisticated genomic analyses demonstrating how populations migrating from Liberia actually "reintroduced" the Ebola virus back into Guinea in multiple waves [51]. Fourth, the classic analysis of the "coupled contagion dynamics of fear and disease" illustrates that, in the case of infectious diseases, fleeing actually increases risks for viral transmission [4•].

The behavioral choice that effectively limits spread involves isolating and restricting the movement of cases. This was the ETU option. By foregoing available ETU care, those who fled actually increased their risks for infection. The "hazard" hitched a ride with those who were trying to escape, in the form of Ebola virus incubating in asymptomatic individuals who were migrating.

# FRBs Impeded the Utilization of Life-Saving EVD Treatment

FRBs that impeded the utilization of life-saving EVD treatment: FRB4: Avoiding or foregoing available, life-saving Ebola treatment FRB5: Health-care workers defecting from hazardous duty

Even in the absence of efficacious medical treatments, the application of basic rehydration and supportive care, provided under strict infection control conditions in ETUs, increased survival rates. Nevertheless, several fear-based behaviors impeded access to and use of these facilities and services.



Fearful persons with EVD symptoms often declined to seek care in medical facilities and avoided admission to the ETUs [19•, 21, 38••]. Although chances of survival were improved in the ETUs, about half of the patients treated in the specialized units died. Family and community members could objectively observe that many patients who entered these facilities never reappeared. Furthermore, in the first year of the outbreak, family members were prohibited from visiting the patients while alive and barred from retrieving the infectious cadavers following death. Understandably, these circumstances conspired to trigger widely held beliefs that the medicine being practiced inside the treatment units was dangerous or deadly [1••, 2•, 8, 19•, 41, 52, 53].

There were also instances where some health professionals treated Ebola patients in their homes or in private clinics without proper protection and did not refer these patients to ETUs or isolation units. By avoiding care in the ETUs and remaining in the community, EVD patients both decreased their personal chances for survival and increased their encounters with susceptible, noninfected citizens in household or public settings. There were also reports that a number of admitted patients, after witnessing suffering around them, fled from the treatment units, carrying their disease back into the community [1••, 2•, 19•].

FRB5: Health-Care Workers Defecting From Hazardous Duty

Some health workers abandoned their duties, choosing not to put their lives on the line. This was in sharp contrast to hundreds of their counterparts who worked heroically at extreme personal risk [5•].

Researchers have studied health workers' "willingness to serve" during virulent disease outbreaks, demonstrating conclusively that some professionals will abdicate rather than risk becoming ill and possibly infecting their own family members [2•, 54–57]. The 2013–2016 EVD outbreak put these hypothetical scenarios to a real-world test. Some workers took extended sick leave or simply left the workforce entirely [19•]. Several international humanitarian organizations that had been providing medical care services in the pre-Ebola era opted to pull their staff from the area [42•, 58]. For a critical period of time while Ebola cases were surging, bed availability actually declined [42•]. The wholesale loss of health workers due to illness, death, and job abandonment caused some medical clinics and mental health centers to close [2•, 3, 42•, 59], further hobbling the imperiled health system and impeding access to care.

Notes from the Field In the opening months of the outbreak, some courageous health workers provided care despite the



lack of proper personal protective equipment and many became infected and perished in high numbers [2•, 5•, 42•, 60–62]. Fortunately, from an infection control standpoint, protective equipment was brought to the field and distributed to frontline workers who were carefully trained on proper procedures for donning, doffing, and operating in the suits.

The extreme difficulty and discomfort of working in protective suits, particularly in the high-humidity tropical environs of West Africa was physically exhausting and psychologically stressful and fear provoking [2•, 19•, 53]. Working while completely shrouded in impervious fabric, health workers were drenched in perspiration while experiencing labored breathing, sweat-blurred vision, air hunger, and claustrophobia. Grappling with the fog of fatigue, some professionals became infected when they accidentally breached some element of the elaborate protocols for safely putting on or removing the suits [63–65].

Used meticulously, protective equipment shields health workers from infection risks but also creates a physical barrier to communicating with patients [53]. Performing medical duties while draped head-to-boots, and wearing a mask and face shield, made it difficult to communicate essential information to patients, to make eye contact, and to convey compassion [53, 59, 65].

# FRBs Curtailed the Availability of Medical Services for Treatable Conditions

FRB that curtailed medical services for treatable non-Ebola conditions: FRB6: Avoiding life-saving treatment for non-Ebola conditions

FRB6: Avoiding Life-Saving Treatment for Non-Ebola Conditions

During the 2013–2016 EVD outbreak, an estimated 10,600 preventable deaths occurred from inadequately managed cases of malaria, tuberculosis, and HIV [2•, 66, 67•]. Meanwhile, infant and maternal mortality rates spiked as hospital and professional-attended deliveries declined [2•, 68, 69]. Added to direct fatalities from EVD (11,325), these preventable "indirect" deaths (around 11,000) effectively doubled the mortality from the 2013–2016 outbreak, raising the death toll to more than 22,000 deaths [2•, 3, 5•, 66, 67•].

Avoiding medical treatment was not limited to Ebola care (the focus of FRB4). Generalized fear of using health-care services caused many citizens with treatable, non-Ebola ailments to forego routine clinical care. These persons were fearful that they could contract Ebola if they sought services in clinical settings. Furthermore, they feared that Ebola would be

detected during a medical workup and they would be remanded to the feared ETUs [39••].

These fears were not unwarranted. Non-ETU health-care facilities served as major focal points for nosocomial transmission of Ebola virus [70, 71]. An international team of disease modelers estimated that more than 38 % of EVD cases had been infected in hospital settings through mid-2014 [37]. Indeed, a total of 898 health-care professionals were diagnosed with EVD based on exposures in the clinic and hospital environments where they worked [5•].

Unlike the specialized ETUs, hospitals provided care to a general patient population. Therefore, health-care venues presented the possibility that Ebola virus-infected persons could be among the patients using the common facilities including waiting rooms and examination rooms. Clinicians were not regularly using the level of protective equipment worn by personnel in the specialized units and ETUs [71].

**Notes from the Field** The impact of FRB6, avoiding available, life-saving treatment for non-Ebola conditions, was amplified by a more complex array of factors that diverted healthcare resources away from routine care.

First, treating Ebola was the urgent top priority based on realistic fears of escalating spread of this deadly disease. Ebola care required heavy staffing ratios, particularly due to the difficulties of delivering care in short bursts of time due to the rigors of wearing protective suits. The need to treat Ebola necessarily redirected health personnel away from the care of patients with endemic ailments. Given the fear-fueled focus on treating Ebola, the consequences of neglecting the care of patients with HIV, malaria, and tuberculosis were not fully apprehended, resulting in a preventable loss of life almost equal to the direct mortality from EVD itself.

Second, health professionals were in short supply when Ebola emerged (e.g., Liberia had 110 physicians including just one psychiatrist) [72]. Almost immediately, the ravages of Ebola severely depleted this meager health-care workforce, including the poignant loss of some of the most venerated professionals [61]. Health-care workers sustained a rate of Ebola mortality that was 50 % higher than for nonhealth professionals [5•]. More than 500 health-care professionals lost their lives across the three intense transmission nations, representing 8 % of physicians, nurses, and midwives in Liberia; 7 % in Sierra Leone; and 1 % in Guinea [66, 73].

Third, the hundreds of health workers who died were local assets, the mainstay of personnel who normally treated the prevalent diseases. With the pressing demands of treating Ebola, there were no replacements to "backfill" the vacancies and there were no reinforcements arriving to help with usual, non-Ebola care. The international health professionals came to treat EVD, not other diseases.

Fourth, some of the international NGOs that responded to the pandemic hired local personnel, offering much higher



wages than the local health facilities could pay. Health professionals who were so critical for providing routine health care were lured away to work in the ETUs. Meanwhile, local hospitals languished with declining rates of patronage, inpatient admissions, and surgical procedures [74].

# FRBs Increased Risks for Psychological Distress and Psychiatric Disorders

After years of primarily anecdotal accounts that described widespread fear responses, research on psychosocial and mental health consequences of the 2013-2016 outbreak is beginning to emerge, with authors emphasizing that Ebola was a "traumatic illness" [24•, 75••]. A just-published landmark study of 1008 respondents from rural and urban districts of Sierra Leone, surveyed during the peak of the outbreak, found that "individuals reporting greater intensity of depression symptoms and higher rates of PTSD symptoms also reported higher rates of behaviors that increase the risk of spreading EVD" [75••]. Among the primary risk behaviors included in the analyses were actions that qualify as FRBs (FRB1: Keep them (family members with EVD) at home and provide care, Get help from my family at home; FRB4: Move them to another location that is not an Ebola treatment center where I know that family or friends who I know would take care of *them*) [75••].

Ebola's psychological impact will be differentiated by the severity of exposures to trauma and loss. The most identifiable individuals who are likely to experience serious and enduring psychological consequences are the 17,000 survivors who have recovered from EVD [5•]. A qualitative study of Ebola survivors who have received care in an ETU determined that psychological distress was widespread and related to direct exposures to suffering, death, and corpses left visible and unattended on the units while they were in treatment [29••].

FRBs that increased risks for psychological distress and psychiatric disorders:

FRB7: Stigmatizing Ebola survivors and EVD family members FRB8: Blaming, attacking, and stigmatizing health workers

FRB7: Stigmatizing Ebola Survivors and EVD Family Members

With more than 28,000 total cases and a 39.5 % case-fatality rate, the 2013–2016 EVD outbreak produced more than 11,000 deaths [5•]. The obverse is equally important to consider; the "survival rate" was 60.5 %; more than 17,000 EVD patients recovered from illness [5•]. All survivors dealt with a life-threatening illness that carried a powerful psychological overlay and qualified as direct trauma exposure for possible development of posttraumatic stress disorder (PTSD) [24•,

75••]. Survivors remained physically weakened long into the recovery period and many continued to experience symptoms of "post-Ebola syndrome" [76].

Adult Survivors For many EVD survivors, recovering from a grave illness was just the first challenge. Survivors frequently encountered stigma, rejection, and shunning at the hands of their own family members and neighbors [8, 24•, 29••, 77, 78]. As Rabelo et al. summarized, "when EVD survivors returned home, the experience of being alive was both a gift and a burden" [29••]. Although "they came back from the dead," while they were in treatment many lost family members to EVD. They had not participated in the mourning rituals, and in the case of cremation, no gravesite existed to pay respects to lost loved ones.

Stigma took many forms. Some recovered EVD patients returned to their communities to find personal property destroyed and homes looted or even burned to the ground [29...]. Survivors were widely believed to harbor infection and the post-Ebola somatic symptoms reinforced this misperception [29., 52, 58, 76]. Based on misguided fear of contagion, some survivors lost their jobs or were unable to sell their products in the local marketplace [24•, 29••]. In some instances, discrimination escalated to levels where survivors were forced to divorce, banned from public places or religious gatherings, victimized by acts of interpersonal violence, or even banished from the community [29.]. Heaped upon the trauma of experiencing EVD illness and the loss of family members to the disease, Rabelo and team [29. described a harsh homecoming marked by ostracism, rejection, isolation, humiliation, and exclusion. Unable to regain their lives and livelihoods, survivors were very likely to experience symptoms of depression and posttraumatic stress disorder [29., 75., 79]. Recognition of the extreme difficulties faced by persons attempting to return to their home communities following discharge from the ETUs, CDC and other humanitarian actors developed "reintegration" and support programs to assist survivors [80, 81].

**Child Survivors** Children were disproportionately affected by the EVD pandemic. UNICEF estimated that children accounted for one-in-six total cases and almost one third of the deaths [82]. The case-fatality rate for child cases of EVD was 73.6 %, more than twice the 32.7 % rate for adult cases. The 1,260 child "survivors" of Ebola face lingering medical symptoms and social challenges.

UNICEF also estimated that a much larger number of children—about 23,000—lost a parent (or both parents), or a primary caregiver, to EVD [82]. Some of these children not only lost their parents, they were ostracized, stigmatized, or abandoned in their home villages. Not calculated in this estimate is the number of children who were "orphaned" by the loss of



parents or caregivers due to preventable deaths from treatable diseases and maternal deaths due to unattended childbirths.

FRB8: Blaming, Attacking, and Stigmatizing Health Workers

Health workers and other humanitarian helpers were sometimes doubly jeopardized. First, each day, they faced viral infection risks in the line of duty. Second, some workers were intentionally targeted for harm based on misperceptions that they were actually spreading disease or killing patients [39••].

Distrust of Ebola medical care, laced with misinformation, may have incited the violence that left eight health educators dead and 21 injured when they visited Womey, Guinea, to educate the population about how to prevent EVD [83]. Later in the outbreak, these fear-provoking situations were partially rectified; in Liberia for example, family members were allowed access to the treatment units once protective suits were available, and community tours were conducted to demystify the image of the ETUs.

Stigma toward health professionals was not confined to Africa. The fact that the USA experienced its first Ebola cases led to extraordinary reactivity [1••, 2•, 23•]. Heavy-handed quarantine restrictions were imposed on returning US health professional volunteers who had served in outbreak-affected nations. These measures diminished the willingness and availability of health professionals to serve in West Africa at a time of critical personnel shortages [84–86].

# FRBs Amplified Cascade-Like Downstream Phenomenon of Stigma and Social and Societal Issues

During the 2013–2016 EVD outbreak, disease and fear contagion were enmeshed with fear-driven behaviors at community and societal levels that together contributed to stigma and spirals of social and economic issues.

FRB that contributed to cascades of stigma and social/societal problems: FRB9: Stigmatizing the intensive transmission nations

First, fear of disease transmission and fear of persons who were perceived to be infectious were entangled with decisions regarding movement restrictions. The public health practice of quarantining individuals, households, and even entire sectors of the community added to the psychological distress [39••, 41, 85, 86]. To this was added the imposition of enforced curfews and border closures with neighboring countries. Stigma was apportioned based on the scope of the public health measure enacted, directed toward an individual, a family, a community, a nation. The repercussions were experienced globally but most intensely in Guinea, Sierra Leone, and Liberia, the highly affected nations that were labeled as "infected countries" [1••].

Second, the pandemic decimated the already highly fragile economy in all three countries. Agricultural production declined and stagnated leading to food insecurity and rationing [42•, 66, 87]. Mass transit was hobbled as word spread that taxis that transported EVD patients were vectors of Ebola infection [42•, 88]. Commercial air flights to the region were cut in half, just one symptom of the international isolation these nations experienced.

Precipitous declines in productivity were accompanied by a large-scale loss of workers in the private sector (e.g., 50 % decline in Sierra Leone) and the public sector, thus weakening an already dysfunctional governance system further [66]. Disease control measures such as quarantines and movement restrictions stifled cross-border trade with neighboring states [89, 90]. As a consequence of these negative economic impacts, the gross domestic product (GDP) cratered in the outbreak epicenter nations [19•, 52, 66, 91]. The World Bank estimated the combined GDP losses for Guinea, Sierra Leone, and Liberia at \$2.2 billion in 2015 alone [66, 92–94].

Third, all three widespread transmission nations are among the United Nations-designated group of "least developed countries" (LDCs). Sierra Leone and Liberia are also considered postconflict nations slowly recovering from decades of war, extreme violence, and deep oppression. Recent research has documented how war trauma interplayed with EVD trauma to increase risks for depression and PTSD [75••]. For these nations, the abrupt and devastating intrusion of the 2013–2016 EVD outbreak severely counteracted progress along the trajectory of recovery and nation-building.

Fourth, media and social media promoted fear messaging and amplified fear perceptions. Outside the intense transmission nations, most of the world witnessed the outbreak vicariously as portrayed in media accounts [20, 23•, 95–99]. In fact, in the USA, the rampant "contagion" of Ebola fear [23•] occurred in the virtual absence of Ebola disease transmission risks [2•, 3]. Nevertheless, the contagion of fear spreads much more rapidly than infectious disease [4•, 23•] and in the case of the 2013–2016 EVD pandemic, worldwide fear wrapped around to severely stigmatize the African epicenter nations that were battling the outbreak.

### **Summary Comments and Future Directions**

This review has described, analyzed, and enumerated a series of FRBs and their potential impacts on risks and epidemiologic outcomes during the 2013–2016 West Africa EVD outbreak (Box 1). What seems apparent is that FRBs exerted considerable influence throughout all phases of the outbreak, leading to increased viral transmission, interfering with effective treatment, contributing to excess indirect mortality from non-Ebola causes, propelling psychosocial distress and risks for



psychiatric disorders, and adding to cascade-like downstream phenomenon of stigma and social and societal issues.

### **Box 1:**

Fear-related behaviors (FRBs): Effects on the 2013-2016 West Africa Ebola Virus Disease Pandemic

FRBs that accelerated the spread of Ebola virus and EVD:

FRB1: Providing Ebola care in home settings

FRB2: Conducting unsafe body cleansing and burial practices

FRB3: Fleeing from home communities/migrating to new settings

FRBs that impeded the utilization of life-saving EVD treatment:

FRB4: Avoiding or foregoing available, life-saving Ebola treatment

FRB5: Health-care workers defecting from hazardous duty

FRB that curtailed medical services for treatable non-Ebola conditions: FRB6: Avoiding life-saving treatment for non-Ebola conditions

FRBs that increased risks for psychological distress and psychiatric disorders:

FRB7: Stigmatizing Ebola survivors and EVD family members

FRB8: Blaming, attacking, and stigmatizing health workers

FRB that contributed cascades of stigma and social problems:

FRB9: Stigmatizing/isolating the intensive transmission nations

#### Lessons Learned From the 2013–2016 EVD Outbreak

The focus on the 2013–2016 EVD outbreak yields important lessons. Consider that once the random, singular spillover event occurred (Ebola virus transmitted from a wild animal reservoir to a young human child), the propagation of the remaining 28,000 outbreak-associated cases was driven by human behaviors. The expression of FRBs potentiated the spread of disease.

How did FRBs play a role? With communicable diseases, the early cases exert disproportionate effects on the downstream cascades of infection. Therefore, some of the initial behavioral choices—to treat patients in home settings, to forego Ebola care at the treatment units, to avoid clinic-based care for non-Ebola conditions, and to continue hands-on funeral practices—contributed significantly to amplifying the magnitude of the 2013–2016 EVD outbreak.

FRBs are potentially preventable; had their effects been minimized early in the outbreak, some sizeable proportion of the outbreak-associated morbidity, mortality, economic costs, and socio-ecological consequences might have been circumvented. Quantitative modeling is yet to be conducted, but a significant proportion of the EVD cases and deaths could potentially have been prevented by intervening on FRBs. Particularly compelling was the unnecessary loss of 11,000 lives to illnesses that could have been treated effectively; these were primarily deaths from HIV, malaria, and tuberculosis, coupled with excess maternal and neonatal mortality related to unattended childbirths.

Here are five specific lessons learned from the 2013–2016 EVD outbreak:

- Apply the "science" of health communication early on and resist the temptation to show grotesque images that research suggests did not work but accelerated the spread. EVD survivors tell us that the early message that EVD kills everyone that gets it was one that contributed to the spread.
- Recognize that communities that endured unresolved trauma are more likely to respond to the cumulative effects of traumatic events. In Liberia, the dead bodies in the street from EVD were eerily similar to dead bodies from the civil war. Peacetime is the time to address past psychological trauma.
- 3. Attend to the social fabric of the society. Evidence from SARS and the EVD outbreak shows that communities where social cohesion and trust were high did a good job of pulling together, following basic norms about keeping safe. Those communities in Liberia that didn't believe the government tended to be the ones that denied, often at their peril, the reality of EVD.
- 4. Create a robust health-care system that engenders trust and attenuates fear. The global health community ought to attend to those countries with weak health-care systems since they can and will end up exporting the next infectious epidemic.
- Devise communication and awareness-raising strategies, behavioral interventions, risk governance, and community engagement approaches that can diminish the disease impact of FRBs in the future pandemics.

### The Study of Fear-Related Behaviors

The study of FRBs is best conducted collaboratively, linking expertise from the disciplines of disaster psychiatry, medical anthropology, disaster behavioral health, public health, emergency medicine, emergency management, and risk governance. Examining FRBs prioritizes the very central role played by psychological reactions that transform into behaviors that in turn, produce a range of consequences in situations of mass threat.

Co-authors and colleagues representing these complementary disciplines are exploring how to quantify and model FRBs to provide actionable guidance for planning and intervening in future pandemics as well as a broader range of disasters and extreme events. Initial observations regarding FRBs include the following:

 Fear-related behaviors (FRBs) are amenable to modification in a manner that decreases the risk of physical and psychological harm and improves public physical and



mental health. The corollary is that fear and fear reactions can also be manipulated to amplify risks (as what happens in acts of terrorism).

- Creating an operational definition of FRBs is an important step toward quantification, detection, monitoring, and timely modification.
- FRBs can be modeled and used for scenario development and complex action planning in the context of risk governance.
- To the extent that risk-elevating FRBs can be prevented, mitigated, or modified, harm (morbidity, mortality, economic costs, and sociocultural consequences) may be diminished. Moreover, mitigation of FRBs will support the effectiveness of governance systems and public order, especially in least developed countries.

### Future Directions for the Study of FRBs and the Link to Disaster Mental Health

The study of FRBs is applicable to a wide range of mass threat and mass casualty scenarios. Infectious disease epidemics, as exemplified by the 2013–2016 Ebola outbreak or pandemic influenza, are potentiated by FRBs. FRBs are integral determinants of the severity of physical, psychological, and social as well as societal consequences across the continuum of emergencies, disasters, and catastrophes. FRBs are highly relevant during intentional human-generated events, particularly when harm is purposefully inflicted to elicit fear and terror—and to propagate FRBs themselves—for political or ideological purposes.

Among the many disciplines at the forefront in the exploration of FRBs, and the development of strategies to decouple FRBs before they set off cascades of consequences, none is more important than disaster mental health. Disaster psychiatrists will be called upon to provide key leadership. As a starting point, one of the legacies of the 2013–2016 EVD pandemic will be that of laying the groundwork for investigating, understanding, and intervening on FRBs.

### Take Home Points on Fear and FRBs

Fear as a Protective Factor

Fear is critical to species survival.

Fear of mass threats, including pandemic infectious diseases, is widespread, normative, understandable, and expectable.

Fear may be channeled and redirected in a manner that decreases risk.

Fear as a Risk Factor

Fear may spread within a population by contagion.

Fear creates fear. Fear propagates fear. Fear amplifies fear.

Fear may distort risk perceptions.

Fear messaging in the media disseminates fear and distress

Fear may be purposefully manipulated for political purposes.

Fear-Related Behaviors (FRBs)

Fear generates fear-related behaviors (FRBs).

- FRBs include preventive and protective behaviors.
- FRBs include actions that elevate risk and increase harm.

FRBs may spread across a population by contagion.

Media and social media messaging may broadly disseminate FRBs.

The expression of risk-elevating FRBs is potentially preventable.

FRBs in the 2013-2016 West Africa EVD Outbreak

FRBs were associated with:

- Increased transmission of Ebola virus
- Increased rates of EVD cases and deaths
- Avoidance of life-saving treatment for EVD in specialized treatment units
- Avoidance of life-saving care for treatable non-EVD conditions
- Increased psychological distress and psychiatric disorders
- Increased societal stigma and discrimination directed ed toward peoples and products of highly affected nations

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#### Compliance with Ethical Standards

Conflict of Interest James M. Shultz, Janice L. Cooper, Florence Baingana, Zelde Espinel, Benjamin M. Althouse, Louis Herns Marcelin, Sherry Towers, Maria Espinola, Clyde B. McCoy, Laurie Mazurik, Milton L. Wainberg, Yuval Neria, and Andreas Rechkemmer declare that they have no conflict of interest.

Maria A. Oquendo receives royalties for the use of the Columbia Suicide Severity Rating Scale. Her family owns stock in Bristol Myers Squibb. Dr. Oquendo receives a stipend from the APA for her service as president.



**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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