

# Reflections on the Ebola Public Health Emergency of International Concern, Part 2: The Unseen Epidemic of Posttraumatic Stress among Health-care Personnel and Survivors of the 2014–2016 Ebola Outbreak

## INTRODUCTION

Neither dramatic footage nor horrifying statistics from the most recent Ebola virus (EBOV) outbreak come close to reflecting the true impact of the EBOV disease (EVD) on affected countries, communities, patients, health-care workers, or their friends and families.<sup>[1,2]</sup> With focus squarely on containing the outbreak and dealing with the immensity of the task at hand, many fail to notice the associated emotional and psychological toll.<sup>[3,4]</sup> Posttraumatic stress disorder (PTSD) is defined by Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition as a specified constellation of emotional and behavioral responses to traumatic events.<sup>[5]</sup> The affected person frequently reports an exposure to death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence. Within this context, one or more of the following are required to meet the diagnosis of PTSD: (a) direct exposure to trauma; (b) witnessing the traumatic act or event in person; (c) indirect involvement, by learning that a close relative or close friend was exposed to trauma; (d) if the event involved actual or threatened death, it must have been violent or accidental; and (e) repeated or extreme indirect exposure to aversive details of the event(s) has occurred, usually in the course of professional duties (e.g., first responders, collecting body parts, social workers repeatedly exposed to details of child abuse).<sup>[5]</sup> This does not include indirect nonprofessional exposure to above-mentioned events through electronic media, television, movies, or pictures. In this Editorial, we will discuss the very real and well-documented phenomenon of PTSD among EVD survivors, caretakers, and their immediate contacts.

## HEALTH-CARE STAFF PERSPECTIVE

Imagine working in an environment where providing care is intimately tied to the likelihood of contracting a potentially lethal disease. Imagine the burden of constantly living and working under the gravest of circumstances. Imagine witnessing deaths of hundreds of people, caused by the hemorrhagic fever of the worst kind. This was the terrifying reality of being a volunteer physician during the 2014–2016 Ebola outbreak in West Africa.

## POSTOUTBREAK EFFECTS OF EBOLA ON HEALTH-CARE STAFF

The tremendous need for health-care services during the Ebola outbreak was associated with substantial risks and

stressors (both physical and psychological) to health-care workers.<sup>[6]</sup> During outbreaks, health-care providers must balance the fundamental “duty to treat” with the parallel duty to family and loved ones.<sup>[7,8]</sup> Manifestations of individual struggles and conflicts regarding the prioritization of personal versus societal duties were evident through reports of health-care personnel abandoning medical facilities.<sup>[9]</sup> Regardless of justifications provided, such actions resulted in increased personal stress and substantially elevated levels of risk among remaining staff members.

The emotional burden of exposure to an event as massive and overwhelming as a deadly disease outbreak may not be immediately apparent among the staff who tended to those affected by EVD.<sup>[10]</sup> It has been noted that majority of those who are exposed to highly stressful, emotionally charged situations have sufficient resilience to avoid long-term adverse mental health sequelae.<sup>[11]</sup> However, this assumption is neither absolute nor universally applicable, and inevitably some of the health workers exposed to significant emotional and psychological burden may develop signs and symptoms of PTSD. Many of the caregivers who tended to those affected by EVD were from the local workforce and had to treat acquaintances and neighbors. Witnessing the loss of those within one’s immediate circle of social contacts may result in significant psychological trauma.<sup>[12]</sup> Even more stressful and impactful may be the loss of a colleague/team member, making palpable the dangers of the work involved and the very real risk of one’s own mortality. Situational demands often force the participants to “carry on and defer” the grieving process until later, especially during massive and difficult-to-control events that occurred during the Ebola outbreak. Hundreds of front-line health-care workers contracted EVD, with approximately half of them ultimately dying.<sup>[13]</sup> Of note, both grieving caretakers and families were forced to deal with the loss of life while processing their own survival in the setting of significantly decreased social support.

It is well known that EBOV arouses deep fear in outbreak-affected areas. This “fear response” includes corresponding behavioral changes associated with traumatic personal experiences such as witnessing actively symptomatic patients, the bodies of the deceased, and the grief of the loved ones who lost a family member.<sup>[10,13]</sup> It has also been reported that due to the high mortality associated with EVD,

various myths and misinformation contributed to deep distrust among local populations, resulting in violence misdirected at health-care workers.<sup>[14]</sup> Likely reflective of “collective PTSD” manifestations within the community, the fear, anxiety, distrust, and emotional stress experienced by volunteer workers were further compounded by physical exhaustion, frustration at the scarcity of available health-care resources, poor management of mission goals, problems with assignment of roles and responsibilities, as well as the inability to deliver the high quality of care normally expected by developed world standards.<sup>[15]</sup> The paradoxical behavior of turning against the very providers trying to help those afflicted was often due to irrational fears and superstitions among local populations.<sup>[10]</sup> To further compound the psychological pressure, some of the health-care professionals returning to their native countries or communities were faced with a potentially stressful 3-week period of relative isolation including limited contact with their friends and loved ones.<sup>[8,16]</sup>

An additional challenge facing those who are actively fighting an outbreak as deadly as EVD (e.g., case fatality rate >50%) is that health-care providers may experience and overwhelming feeling of helplessness.<sup>[17]</sup> This has been well documented in the fields of oncology and critical care where physicians have a higher likelihood of facing end-of-life scenarios than providers in other specialties.<sup>[18,19]</sup> Furthermore, the intensity of caring for patients with EVD (e.g., the requirement to avoid skin contact and the donning of personal protective equipment) may also be an independent contributor to burnout, leaving providers with feelings of social isolation.<sup>[20]</sup> Burnout and PTSD are closely related, and increasing duration of burnout may result in a higher likelihood of developing PTSD.<sup>[21]</sup>

Posttraumatic stress is considered to be a well-established risk among health-care workers facing deadly outbreak or disaster events.<sup>[3,16]</sup> Experiences during previous epidemics such as the severe acute respiratory syndrome (SARS) and the early experiences with human immunodeficiency virus (HIV) can serve as valuable templates for the understanding, diagnosis, and management of associated mental health complications including PTSD.<sup>[22-24]</sup> What are sponsoring organizations to do when their workers and volunteers are sent abroad to face potential “live or die scenarios” under immense psychological pressure? It has been suggested that the deployment of preventive initiatives should be considered early in the course of preparation and implementation of medical assistance programs.<sup>[16]</sup> Of course, this is easier said than done, especially in the setting of relative lack of definitive guidance and/or resources. Resilience and coping mechanisms which enable first responders to appropriately balance work-related mental health are topics of increasing interest and research.

## EBOLA SURVIVOR PERSPECTIVE

Imagine being a patient in a busy, makeshift field hospital in West Africa. Imagine being infected with one of the most terrible viral illnesses known to humanity. Imagine seeing

people just like you, suffering, and dying all around you with little to no ability to alter the terrible toll on these individuals. Imagine not knowing if you will live another day or die from an overwhelming hemorrhagic fever. This was the frightening reality of being a patient during the 2014–2016 Ebola epidemic that engulfed Guinea, Liberia, and Sierra Leone.

## EBOLA SURVIVORS

When considering PTSD among the patient population during the 2014–2016 Ebola outbreak, one must take into account various complex relationships between local cultural factors and posttraumatic stress. Mental health issues in general tend to be relatively neglected in low and middle income countries.<sup>[25]</sup> To further compound the problem, there have been reports of fear and mistrust of authorities, including foreign health workers, in areas devastated by the Ebola outbreak.<sup>[26]</sup> The same mistrust that may have led to behaviors that contributed to the spread of the illness also made challenging the mental health outreach and treatment intended to assist the affected populations. In the context of PTSD, opinions vary on how culture plays a role as a modulating factor.<sup>[27]</sup> Specific views range from PTSD being a culture-specific condition created by the Western world<sup>[28]</sup> to the more broadly accepted idea that PTSD is a clearly defined mental health disorder which, nevertheless, cannot be decontextualized from cultural influences.<sup>[29]</sup>

Given the above considerations, one must be aware of the possible lack of acknowledgment and cultural awareness regarding PTSD in the West African population – the majority of those affected by the 2014–2016 EVD outbreak. This may, in turn, influence preventive measures and treatment of EVD-associated PTSD including its sequelae. Moreover, general approaches that may be effective in Western countries may not have the desired effect in West Africa. Severely limited resources further complicate the problem and amplify its magnitude. In 2015, a World Bank report noted that the number of mental health workers (including psychiatrists) in the local population was as low as 1 in 6 million in Sierra Leone and 1 in 25,000 in Liberia.<sup>[25]</sup> This clearly exemplifies the tremendous need for both additional resources and novel approaches in outreach and treatment of mental health burden in West Africa.

In addition to cultural considerations, other socioeconomic factors play a considerable role when assessing the impact of Ebola outbreak on West Africa. Countries that experienced the largest number of deaths during the 2014–2016 outbreak also had a recent history of armed conflict. Both Sierra Leone and Liberia struggled with civil unrest, civil war, and rebellion in the early to mid-2000's.<sup>[30,31]</sup> In Guinea, political violence and inter-ethnic clashes broke out in February 2013, less than a year before the EBOV epidemic.<sup>[31]</sup> Analysis of PTSD in these countries should consider the trauma experienced by local populations prior to the Ebola outbreak. Indeed, one opinion is that the above-mentioned armed conflicts and/or their

aftermath directly increased the opportunity of transmission of the EBOV from natural disease reservoirs to humans by "... disrupting livelihoods and living arrangements."<sup>[31]</sup>

A cross-sectional survey showed that depression and PTSD increased EVD-related risk behaviors, such as waiting to see if symptoms subsided, attempting to treat symptoms at home with traditional remedies. In fact, preventive behaviors that are beneficial in the setting of Ebola outbreak, such as hand washing and avoiding large social gatherings, may be decreased in those with PTSD.<sup>[32]</sup> This raises the concern that not all PTSD in the West African population stricken by the most recent Ebola outbreak can be directly attributed to the disease itself. Consequently, a new aspect of PTSD that is unique to Ebola is introduced and only re-affirms the need to aggressively prevent and treat posttraumatic stress, especially in areas vulnerable to, or already affected by, an outbreak.

It is now well established that Ebola survivors and their relatives are prone to develop significant psychological distress.<sup>[33]</sup> This is not a phenomenon isolated to those affected by Ebola, with as many as 10% of survivors of the 2003 SARS outbreak reporting PTSD symptoms.<sup>[34]</sup> Due to lack of systematic study of the problem during previous Ebola outbreaks, it is difficult to precisely quantify the magnitude of this mental health burden.<sup>[35]</sup> Qualitatively, many survivors shared their perceptions of being judged or accused, feelings of shame or rejection, and the fear of becoming gravely ill.<sup>[35]</sup> Thus, survivors of EVD not only have to face the traumatic experience of contracting the disease and suffering from it, but also the postexposure stigma within a society collapsed by the outbreak. Unfortunately, some of these perceptions turn into a harsh reality when survivors return to their communities – experiences previously described by patients and health-care workers exposed to and infected with HIV.<sup>[36]</sup> In this context, reintegration into the community is negatively affected by fear, stigma and misconceptions, as well as the breakdown of social networks. Consequently, the survivor may be overwhelmed by combined experiences of both grief/personal loss, rejection, and PTSD (e.g., anxiety, depression, mistrust).

A more recent experience from the 2014-2016 outbreak examined a broad range of individuals exposed to the emotional burden of Ebola, from direct survivors, to their families, to more distant personal contacts.<sup>[33]</sup> The authors found that nearly 39% of surviving respondents faced difficulty concentrating on tasks, 33% experienced problems with sleep due to worry, with 5%–10% of respondents reporting feelings of worthlessness, inability to make decisions, or losing confidence in self.<sup>[33]</sup> Of note, the proportion of respondents who answered positively to most of the survey questions decreased with increasing "distance" from the actual outbreak survivors.<sup>[33]</sup>

It must be emphasized that fear-related behaviors (FRBs), or reactions to actual or imagined threats to lessen the perceived impact of an event or disease at the level of the individual, were relatively frequent during the outbreak.<sup>[37]</sup> Commonly listed

concerns included fear of the disease agent and its reservoirs, its symptoms, the care environment, and the government response (checkpoints, home searches, quarantine, etc.) that resulted in population flight, abandonment of patients by caregivers, hurried and unsafe burial practices, and social stigmata. Such FRBs further contributed to post-Ebola PTSD because they may have led to: (a) limited availability of services for other treatable conditions; (b) suboptimal delivery of lifesaving Ebola interventions; (c) increased social problems during and after the outbreak; and (d) the potential for accelerated spread of the virus.

Grief is defined as the emotional, behavioral, social, and functional response to loss. People experience traumatic events throughout their lifetime. Although inherently personal in nature, grief may also be associated with losses due to large-scale precipitating events such as natural disasters, wars, and epidemics.<sup>[38]</sup> Pandemics, epidemics and outbreaks have unique characteristics that affect people at both deeply personal and population levels. Grief, anxiety, and depression represent some of the emotional responses associated with trauma. The loss of life (and the fear thereof) can have profound and lasting effects as well. Given its high case fatality rate, EBOV infection tends to impact communities in a number of unique ways. Along with the anxiety, fear and uncertainty associated with a potentially fatal illness at the level of "self" are the impacts of physical and social isolation, as well as the stigma generated by the overall "fear response". The actual or effective quarantining of entire communities, combined with the massive loss of life add to the emotional trauma and are major contributing factors in the development of significant anxiety, grief responses (e.g., PTSD) and survivor's guilt.<sup>[39]</sup> As discussed earlier, this "psychological syndrome" is similar to that seen among patients affected by other incurable or overwhelming disease states.

As outlined above, grief and PTSD seem to be the predominant mental health issues observed during and after an outbreak event.<sup>[40]</sup> Manifestations among affected individuals may vary along the severity spectrum, with behavioral issues and substance abuse on one axis and the transference of stress reaction from the family's adult members to children on the other axis.<sup>[40]</sup> In a relatively recent report from Sierra Leone, over 20% of individuals affected by EVD demonstrated signs of PTSD.<sup>[41]</sup> Authors cited significant contributory stressors to include loss of immediate family member, witnessing the death of a loved one, fear of re-experiencing the traumatic event, and the perception of being somehow "marked" or carrying a stigma.<sup>[41]</sup> As mentioned earlier, there may also be the so-called "survivor's guilt", where affected individuals perceive themselves as having done something wrong by surviving a traumatic event, in which others died.<sup>[42]</sup>

To further compound the problem, it is increasingly apparent that the EBOV may stay dormant within one's body and there is a low – yet terrifying – possibility that a reactivation could result in a relapse of the acute illness.<sup>[7]</sup> Various



“immunologically privileged” areas of the body with lower immune defense penetration, such as eyes, testicles, and spinal column, may harbor the virus long after its apparent clearance from the serum on routine diagnostic testing.<sup>[43,44]</sup> These “safe harbor” anatomic areas for the EBOV have been implicated in the possible sexual transmission of the disease from a Liberian survivor to their partner through semen, months after initial recovery from EVD.<sup>[45,46]</sup> The ramifications of this possibility and psychological impact on intimacy for survivors and their partners can be significant.

Finally, long-term sequelae of Ebola are not confined to mental health issues. In fact, a number of neurologic and systemic conditions are now being identified and cataloged among survivors, suggesting that those fortunate enough to survive the acute EVD may have to deal with health consequences of the infection for years to come. In one series, 75% of survivors experienced cognitive or psychological symptoms, with insomnia, short-term memory loss, depression, and anxiety among the most common complaints.<sup>[47]</sup> Again, such problems are not unique to Ebola as they are commonly found and well described in patients affected by other serious and life-threatening diseases.

It is critically important that robust community programs for those affected by PTSD are established and actively supported by local, regional, and national governments.<sup>[48]</sup> Social support, combined with positive coping strategies, appears to be instrumental in fostering posttraumatic growth (PTG).<sup>[49]</sup> Favorable response to interventions aimed at promoting PTG, in turn, has been associated with improvements in PTSD symptomatology.<sup>[50]</sup>

The so-called “trauma signature analysis,” a method used during major natural disasters, has been utilized to determine event-specific characteristics, the so-called hazard profile, various associated stressors, the severity of overall exposure, as well as related psychological risks.<sup>[51,52]</sup> In addition to other government-sanctioned interventions, it is important for local and regional agencies to have an effective strategy in place to counteract tendencies to politicize any outbreak and to raise unfounded fears or rumors.<sup>[52]</sup> Continuous, persistent media exposures to highly traumatic events may alone be sufficient to generate undue distress and various mental health concerns.<sup>[53]</sup> Consequently, survivors of EVD should have a mental health specialist involved in their care due to the inherent risk of long-term psychological sequelae.<sup>[54]</sup>

## POSTTRAUMATIC GROWTH

Among the gloom of an overwhelming event that is beyond any one person’s control is the post-outbreak hope for a better future. Despite the widespread loss and tragedy, there seems to be a strong force to carry on with life.<sup>[40]</sup> Although grief continues to be present “in the background,” the foreground of the post-Ebola reality is firmly focused on carrying on in a fashion “as normal as possible.”<sup>[40]</sup> The concept of PTG has been described, where survivors report

increased appreciation of life, enhanced closeness and caring in interpersonal relationships, and better cohesion within the affected community.<sup>[3,55,56]</sup>

In the aftermath of truly massive, overwhelming events, the mental health community should focus on ways of minimizing PTSD while constructively fostering PTG. Characteristics of individuals who are more likely to experience PTG include those who have strong social support networks, optimistic outlook on life, intrinsic religious beliefs, and a sense of purpose.<sup>[57]</sup> It may well be that among survivors of emotionally traumatic events – including epidemics, abuse, trauma, or severe illness – the ultimate outcome in the psychological domain is determined by the “balance” between PTSD and PTG. Within this context, those with strong coping skills are better able to embrace their ability to overcome adversities, while those who cope poorly continue to be “trapped” in the destructive cycle of PTSD and associated negative behaviors.<sup>[58-61]</sup> However, it is also important to realize that extreme cases of PTG might result in unhealthy social behaviors such as medication noncompliance, maladaptive sexual behaviors, or a generalized sense of invincibility, all of which could worsen the prognosis (or disease natural history) in an individual, lead to other associated conditions, or even worse – promote further spread of the outbreak.<sup>[62-66]</sup>

Currently, there is no organized outreach to help EVD survivors navigate PTSD and enhance PTG. However, important efforts made by the United States governments to address PTSD and enhance PTG among military personnel may provide important foundation for addressing post-traumatic stress in EVD-affected communities. In 2012, the White House and key health-care leaders announced a commitment to recognize PTSD symptoms, provide care, and refer veterans and active duty military members as part of the “Joining Forces” Initiative.<sup>[67]</sup> Within this paradigm, first contact nursing providers utilized a PTSD Toolkit, motivational interviewing techniques, and an “expert companion” to establish long-term therapeutic relationships.<sup>[67]</sup> Organized outreach for Ebola survivors should consider the use of this framework in addition to a 10-item PTG instrument.<sup>[68]</sup>

## CONCLUSIONS

Despite the loss of life, psychological trauma, and economic devastation, Ebola-stricken regions of West Africa continue to resiliently rebuild from the 2014–2016 outbreak. Coordinated global action, although somewhat delayed, resulted in full containment of the disease.<sup>[7]</sup> As eloquently stated by the World Health Organization, PTSD related to EVD is “...an emergency within the emergency”.<sup>[69,70]</sup> The lingering toll of the outbreak now takes the form of PTSD as well as the physical post-Ebola syndrome (discussed in the accompanying editorial). Following the demonstration of high effectiveness of a new EBOV vaccine, the future looks much brighter for the affected regions and other locales fearful of the risk of Ebola reemergence.<sup>[71]</sup> For the first time, the fear of a new outbreak

can be moderated by the comfort of having a powerful new tool to stop the spread of this deadly virus. We now may have the time and the resources to focus on those who continue to live entrapped in the realities of posttraumatic fear.

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