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## **POST EBOLA SYNDROME**

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**Key words:** Ebola, God, Faith, Healing

*Submitted: January 2015, Accepted: January 2015*

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In the midst of the Ebola Virus Disease (EVD) outbreak in West Africa, while the attention is solely on Ebola disease patients, there is a growing group of people that are being forgotten --- the survivors (those that have recovered from the EVD). Life after leaving the isolation ward is laden with a lot of surprises that few Ebola survivors talk about. There is a culture of mutism among survivors, which may be due to their own personal quests for privacy and avoidance of stigmatization and discrimination, but for most, due to pressure from family members not to tell their stories for fear of stigmatization.

I desperately sought for accounts of survivors while I was in isolation. That was how I realized how scarce they were. I read a few accounts that talked about having persistent symptoms even several years after being certified Ebola free. I realized that there is a "Post Ebola Syndrome"

that many do not talk about, but suffer privately with no one to share their woes with.

I was discharged from the ward with residual joint and muscle pains which I ignorantly attributed to sleeping on the very thin mattress that was provided in the isolation ward. The joint pains persisted for about 3 months, usually moderate to severe in intensity, unprovoked and migrating from one joint to another. I could wake up one morning and discover a swollen right knee joint which made movement around that joint very painful, oftentimes resulting in a limp and inability to even climb a staircase with ease. The knees, hip joints and shoulder joints were severely affected. Occasionally, I would experience excruciating pain in my wrists or proximal interphalangeal joints. The pains were self-limiting and usually relieved by analgesics.

Many survivors of the previous outbreaks had complained of persistent joint pains up to 7 years after recovery. I had read that survivors suffered from chronic inflammatory complications such as arthritis, but it was not certain why some developed it and others did not. The inflammatory complication is most likely as a result of immunological overdrive which was initiated during the acute infection.

I also experienced chest and muscle pains which subsided only after about 2 months after discharge.

Immediately after my discharge from the ward, I observed fatigue and generalized body weakness which was usually provoked by exertion from attempts at trying to resume daily activities that I used to engage in before I fell ill with the Ebola Virus infection. Activities such as walking to the grocery stores just down the street resulted in dyspnea and fatigue which were relieved by complete bed rest for a day or two. My body somehow found a way to tell when I was exerting myself more than I should and I learned to listen.

Survivors struggle with anorexia and usually only regain their normal healthy appetite after several weeks in recovery. This perhaps may explain why weight gain is difficult during the first few weeks of recovery. Nutrition must be optimum and supplemented with essential vitamins and minerals to aid the body recovery.

Shortly after I was certified Ebola free, I noticed widespread generalized desquamation of my skin especially on the arms, elbows, hands, abdomen and feet. No amount of exfoliation could completely get rid of the scaly patches. The desquamation was of course embarrassing but after one month, it began to subside, although it persisted on the medial aspects of my feet. I studied the feet of other survivors and noted that we all had patches of scaly skin on the medial aspects of our feet. *Could this be a side effect of the heavy disinfection that characterizes the treatment process?*

My hair was often admired by women who wanted to know my routine. Sadly, 2 weeks down the road to recovery, I noticed clumps of long strands of hair falling off my comb, even from barely touching the hair. The hair was not experiencing breakage, but was literally falling off from the roots. The hair loss was generalized but seemed to be more on the frontal part of the scalp. In addition to the hair loss, I observed that the texture of my hair had changed from being curly and coarse to straight and thin. I eventually cut my hair to hide the embarrassment. Incidentally, I had read about hair loss in some EVD survivors while I was in isolation and hoped that I wouldn't suffer the same fate, but I did. Still, it is only hair and, as sure as I have breath, hair can grow again.

Some survivors complain of progressive visual loss with a few going completely blind afterwards.

It is said that chronic uveitis is also a long term complication of the EVD, though the mechanism is unclear. There are some who complain of tinnitus, progressive hearing loss and even balance related problems.

In addition to the physical debilitation of Ebola survivors, they are faced with varying degrees of psychological issues. Some continue to suffer depression, while others experience feelings of guilt, having survived when others died. Post-traumatic stress disorder (PTSD) is often experienced by survivors who suffer from insomnia weeks after discharge and cannot seem to “move on” with their lives. It is now six months after discharge and my symptoms have greatly subsided but the questions still remain unanswered. *What is responsible for these complications? Is it the Ebola virus itself, the treatment or the heavy disinfection?*

There is an urgent need to identify these complications, and better understand them in order to stop their progression. Scientists and

researchers need to conduct longitudinal studies to understand what their root causes are and if there is reversible or irreversible organ damage years down the line. No two survivors are the same, with some having it worse than others. There is therefore a need for Ebola survivors to be closely followed up by psychologists and physicians for at least one year after discharge.

Ebola survivors should not have to be reminded of what it is like to have Ebola virus disease for the rest of their lives. Visual and hearing loss can be halted and reversed and we can raise networks of Ebola survivors who can enjoy rather than endure the second chance at life that they have been given.

**On-line links to the real story of Dr. Ada Igonoh:**

- [www.bellanaija.com/2014/09/15/must-read-through-the-valley-of-the-shadow-of-death-dr-ada-igonoh-survived-ebola-this-is-her-story/](http://www.bellanaija.com/2014/09/15/must-read-through-the-valley-of-the-shadow-of-death-dr-ada-igonoh-survived-ebola-this-is-her-story/)
- [www.huffingtonpost.com/2014/09/22/ada-igonoh-survivor-ebola\\_n\\_5864156.html](http://www.huffingtonpost.com/2014/09/22/ada-igonoh-survivor-ebola_n_5864156.html)
- [www.youtube.com/watch?v=s38vC-h1-5g](http://www.youtube.com/watch?v=s38vC-h1-5g)