

Is Ebola Hiding in the Eyes of Survivors?



Exactly one year after the physician and Ebola survivor Ian Crozier woke from his coma, I met him at an immunology conference in Raleigh, North Carolina, where he'd been invited to present a case study of himself.

For Crozier's interview, I'd secured a key to the hotel's only available meeting space, the elegant "Mahogany Boardroom," with the promise of not touching a

thing. Within seconds, Crozier was doodling on the dry-erase board walls, chattering about how much he “just loved these things” back in medical school. He spun in an armchair, his 6-foot-5 frame hunched, his tousled hair shifting on his forehead; his demeanor was oddly boyish for someone who had just grappled with death.

But Crozier’s post-Ebola symptoms lingered. He fiddled with the recline lever to ease his back pain; he’d pause mid-sentence, mutter ‘dammit,’ then squint his eyes, searching his slippery short-term memory for his of thought.

I started off with something benign: You’ve gotten a lot of press, I said. What question are you tired of answering?

He put down his Sprite can and crossed his arms. He was quiet for a moment. “I’m tired of people not logically linking my case to West African survivors,” he said. “People ought to be tired of hearing one man's story. I'm tired of telling it.”

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On March 29, the World Health Organization [declared](#) that Ebola was no longer a global health emergency—but many people in West Africa are still feeling its effects.

Fifteen-year-old Mohamed Kamara weaves through the crevices in his slum below the Hagan Street clock tower in central Freetown, Sierra Leone, leading me to the three-sided shack where he and his siblings live under the care of their mother’s friend, a woman named Salimatu; they call her “auntie.” If we’re planning to offer him another cold Fanta, he tells me in Krio, we should just give him the money for it, and preferably hand it over before we arrived.

We climb over two toddlers, a rusted cooking pot, and huddle of elderly women squatting on overturned buckets. We duck under a laundry line strung with lacy thongs and t-shirts. The image of Ernest Bai Koroma, the president of Sierra Leone, glares down at us from massive plastic portraits hanging on all four sides of the clock tower, as if his face were pressed up to the pane of an ant farm.

Mo, as I call him, looks about 9 years old. When we first met, I initially mistook him for his younger brother, Musa. A female classmate—three inches taller than Mo—squeezes the tip of his nose as she prances by, wagging it, teasing him. He cracks a shy smile, then wipes it off.

Mo scratches at his eyes, his burning photophobia triggered in the sunlight. My instinct is to bat his hand away, to warn him, “You’ll scratch your cornea!”, but I bite my tongue. A corneal abrasion would hardly exacerbate the fact that he is already going blind.

Mo is an Ebola survivor—one of the lucky ones who came out of the Ebola Treatment Unit (ETU) “without the zipper,” a local reference to all those carried out in body bags. But in the months following his discharge, Mo’s post-Ebola symptoms were rampant: joint pain, muscle aches, extreme fatigue, difficulty breathing. He had short-term memory loss and couldn’t hear well. Eventually, he noticed that he could no longer make out the words on the pages of his schoolbooks. Over the past year, he has lost all sight in his right eye, which strays off to the side. Now his left

eye is going, too. The virus that ravaged Mo's body, destroyed his family, crippled his country, is back for more.

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In the aftermath of the epidemic, almost half of over 15,000 West African Ebola survivors have exhibited new ophthalmic symptoms that, left untreated, can lead to severe uveitis (inflammation of the eye), cataracts, and blindness. In Sierra Leone, where an already-weak health system has been leveled by the outbreak, ophthalmological capacity is dismal—the country of 6 million people has just three ophthalmologists. And the nightmare is magnified by a frightening curveball: the possibility that live Ebola virus could be replicating in the eyes of discharged Ebola survivors, pleading to be disrupted by instruments and released back into the population.

As long as that question goes unanswered, the eyes of Ebola survivors are considered inoperable. Patients who need surgery are told to go home, to wait, until researchers confirm whether their eyes are viral landmines. Meanwhile, they're going blind.

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Ian Crozier was treating Ebola patients in Kenema, Sierra Leone, when he contracted the virus in September 2014. Often considered the sickest person to ever survive Ebola, Crozier was evacuated to Emory University hospital, where he spent 40 days in an isolation unit, much of it in a coma. After he was released, the virus left him with severe joint and back pain, hearing and memory loss, and extreme fatigue.

Then, months after being declared Ebola-free, Crozier developed severe pain and inflammation in his left eye, a condition called uveitis. His doctors presumed that some common antigen had disturbed the eye due to Crozier's weakened immune

system. When they conducted an eye tap—extracting a few drops of fluid from the anterior (front) chamber of his eye with a needle—Crozier turned to his doctors and, half-joking, told them to remember the moment, “just in case we’re in the middle of a paradigm shift, and the virus is Ebola.”

One morning, he walked up to a bathroom mirror and was sickened to find that his formerly blue iris had turned green.

It was. Doctors were stunned. Though undetectable in his blood, the virus had been squatting for months in the anterior chamber of the eye, perhaps even replicating, without spurring an immune response. In fact, by the time the eye tap took place, the level of virus in his anterior chamber was actually higher than the level in his blood during the peak of the acute infection.

The inner eye joined a growing list of immune-privileged pockets of the body, including the placenta, breast milk, the central nervous system, and the testes, where Ebola could hide. Research on where, how long, and at what concentration the virus can survive is ongoing. But if the virus finds a path out of these strongholds and into the outside world, the effects could be catastrophic.

Crozier says it was a strange first night, lying in bed with awareness that the virus was still hitching a ride in his body. Over the next three weeks, his left eye lost its intraocular pressure, transforming into the consistency Play-doh. Soon after, he lost his sight in the same eye. One morning, he walked up to a bathroom mirror to brush his teeth and was sickened to find that his formerly blue iris had turned green, “a bizarre Blade Runner moment.”

But between an experimental antiviral drug and a steroid treatment, Crozier’s sight began to slowly return. Though his vision is still far from perfect, the eye is now Ebola-free and blue again. Until recently, Crozier was the only Ebola survivor to have had an eye tap, so his physicians don’t know: Was Crozier’s left eye an outlier

phenomenon, or are the eyes of the other 15,000 Ebola survivors teeming with the virus as well?

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Even before the epidemic, Sierra Leone ranked fifth-lowest in the world in the number of doctors per 1,000 patients. Out of the 100 doctors in the country, only about half were practicing clinically, and almost none were specialized. Then the Ebola outbreak struck, redefining the notion of low capacity.

Last February, as the outbreak slowed and survival rates improved, eye complications emerged like a second epidemic. There were hundreds of uveitis cases like Crozier's, but there were also plenty of people with "quiet" eyes (no longer showing inflammation), which had gone untreated and now had complications like cataracts and even retinal and nerve damage. Partners in Health, a global-health nonprofit, stepped in to help coordinate survivor eye care in the country. Groups like Médecins Sans Frontières (MSF), International Medical Corps, and a four-person team from Emory called Quiet Eye West Africa (QEWA) pitched in as well.

"There are real resource limitations in terms of people being reached and screened," says Steven Yeh, the ophthalmologist who headed Crozier's successful treatment at Emory and a member of QEWA team. "Sierra Leone's few ophthalmologists on the ground are doing the lion's share of the work caring for patients."

During the influx in post-Ebola uveitis cases, the Sierra Leonean ophthalmologist John Mattia and two nurses at Freetown's Lowell and Ruth Gess Kissy UMC Eye Hospital were performing cataract extractions on as many as 27 Ebola survivors per day. But when word of Crozier's persistent virus in the United States reached the clinic, it nixed the possibility of continuing even routine eye surgery. A basic cataract surgery—an incision into the cornea to remove a lens and place a new one—would mean that the surgical instruments, and perhaps the health-care providers, would come into contact with possibly infected fluid in the eye. The staff feared,

quite reasonably, that penetrating even a seemingly quiet eye could expose them to a persistent virus or even introduce it back into the population.

“Everything has been based off of that one case,” says Paul Steptoe, an ophthalmic registrar from St. Paul's Eye Unit at the Royal Liverpool Hospital in the U.K. “It’s this idea that, yes, during any survivor’s active uveitis, [it’s possible that] there *is* live virus in the eye, and it *is* potentially as infective as anything else, as even the systemic infection. If you go in, you’re being exposed to live Ebola.”

“If they have cataracts, we just advise them to come back later. We don’t know when. But for now, we just can’t do that.”

Steptoe, who this January spent three weeks in the ophthalmology department of Sierra Leone’s 34th Military Hospital (called MH34), took the first two anterior chamber samples from quiet eyes of Sierra Leonean survivors just last month. Unlike Crozier’s active uveitis case, both quiet-eye samples came back negative for Ebola, meaning those two individuals may be cleared for cataract surgery.

Steptoe acknowledges the potential risk of Ebola virus in the vitreous jelly, farther back in the eye, which has never been tested in an Ebola survivor. (A cataract surgery should only disrupt the front of the eye, but in post-uveitis eyes, there’s an increased chance that fluids in the front and back of the eye have intermingled.) He has since returned to his post in Liverpool, so survivor sampling at MH34 is on hold until he returns next August. A much larger sample size would be needed to demonstrate that quiet-eyed survivors aren’t typically carrying the virus in the front of the eye, but Steptoe’s method was the fast-track way to get a couple of survivors with cataracts into surgery.

Over at the Kissy Eye Hospital, Mattia and his team are waiting on the results of the Emory team’s large-scale clinical trial, which, in typical systematic research fashion (the physicians still practice domestically and visit Sierra Leone a few times per year), seems to be crawling through the planning stages at a glacial pace.

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When the virus first ransacked his family, 13-year-old Mo was the epitome of a middle child. His younger brother Musa had recently started showing him up on the soccer field, and his older sister Maruati refused to share anything. Mo was the closest with his mother. She fell ill four days after attending a burial ceremony for a relative; no one knew what was causing her condition—vomiting, diarrhea, hemorrhaging, and finally, an eerie delirium. When his siblings were sent out to buy rice, visit relatives, go to school, Mo stayed by his mother’s bedside, begging her to recover. She didn’t.

After her death, her blood tested positive for the Ebola virus. Strangers in space suits buried her, and Mo wasn’t allowed to say goodbye. By this time, the Hagan Street slum dwellers had heard of Ebola. Mo and his siblings were outcast from the community. Neighbors had heard the tales of horror and were terrified that the children were carrying the virus. The neighbors were merciless—but they were also right.

Can we remove cataracts in time to prevent their lives from collapsing?

The three children had just been taken into Salimatu’s one-room shack when they began exhibiting symptoms. Mo was taken to MSF’s ETU at Prince of Wales secondary school in Freetown. (Mo later learned that both of his siblings had gone to other ETUs and survived. Salimatu never contracted the virus.) He has no recollection of his time there, aside from snapshots of his favorite nurses standing over him, urging him to eat. Those nurses say he was conscious for much of it; Mo’s amnesia was the first of many signs of post-traumatic stress.

Even when Mo's eye issues escalated quickly—redness, itchiness, almost total loss of vision—he wasn't sure where to seek treatment. He knew he couldn't pay for it. After three months, he was connected to an MSF worker, who immediately traveled with him to Kissy Eye Clinic, where Mattia works. When he came home, he told his auntie what the doctor had said and he wept. So did she.

Mo had undergone the most basic types of vision exams: light projection into the eye, and recognition of hand motion when the hand is waving directly in front of the face. His left eye had a cataract, but he could still see light and motion. His right eye failed both tests.

“If you have some cataract, no matter how dense it is, you should still be able to see something moving in front of it. You should be able to perceive light,” says Steptoe. “If someone doesn't perceive these things, that means it's not just the cataract. There's probably been severe damage to the optic nerve behind it. So even if we took that cataract out, the vision would not be improved.

The Kissy Eye Hospital staff suspect that aggressive pan-uveitis, like Crozier's, had gone untreated as it festered deep in Mo's right eye, ultimately destroying it. Mo returned to the clinic twice more over the course of the year, receiving steroid eye drops and then eventually oral steroids, with no improvement.

Without an anterior chamber tap, it was impossible to tell whether Mo had live virus in his eye, or even case symptoms identical to Crozier's—such as an intraocular pressure change (measured by a more sophisticated instrument than the clinic had), or a color change (since his dark irises masked any pigment shift). They couldn't be certain how, pathologically, the blindness had occurred. In some ways, it didn't matter. The damage was done.

“I don't think Crozier was a unique circumstance. That was probably quite common. There are a lot of patients who have had the same uveitis as Ian Crozier, but they've just not received that level of treatment and examination,” says Steptoe. “Going in now, we're seeing pan-uveitis cases that have burned out, and it's about what kind of damage has been done that remains.”

Mo's auntie is a petty trader, swapping cassava and krain krain leaves in the market to earn a profit. She still owes 180,000 Leones (about \$45 dollars) for the children's school fees. Mo's failing vision has kept him back in the equivalent of sixth grade twice. Salimatu has been clear that if Mo doesn't matriculate, or if his condition progresses to blindness, her foster care will end. Mo will be removed from school, separated from his siblings, and sent to work on his estranged grandfather's farm in the rural provinces.

For Mo, the damage in the right eye was irreversible. Hope hinged on the quiet left eye—also opaque with a cataract, but still reactive to light and motion. It was possible that the uveitis in his left eye had left vital eye structures intact. Two nurses had been trained in cataract removal could have carried out the procedure in under 40 minutes, possibly restoring full vision to the eye. But Mo was an Ebola survivor, and the threat prevailed. After each of the three visits, Mo was told to go home and wait.

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If an adult patient waits a year to remove a cataract, or even two years, a new lens might still restore vision to where it was before the cataract. This isn't true for young children, since their rapidly developing brains begin to favor the strong eye, dissolving the connection with the weak one (called amblyopia). It also isn't true for Mo's right eye, where trauma farther back in the eye has destroyed the potential for his sight to be restored. But for cases like his left eye, theoretically, it's possible.

But if Mo is expelled to the provinces later this year, he may never return to Freetown, let alone undergo a surgery that may or may not repair vision in one eye. For Mo, the chance will be over.

In the boardroom, I asked Ian Crozier about his two-week week flirtation with blindness in one eye. For Crozier, wearing a left eye patch meant swashbuckling with children in U.S. airports and dealing with anxiety over losing the left side of his world. It was a difficult time for him, he said, but not a life-threatening one. He had since returned to Sierra Leone with Emory's QEWA team to develop treatment

protocols and help care for survivors. He told me the story of a boy with circumstances much like Mo's.

“The child is completely alone in the world. Now, I want you to imagine what happens if he goes blind,” Crozier said with an edge in his voice. The boardroom is silent, except a cart of pressed linens trundling down the hall. “Unimaginable. You couldn't script anything worse.”

The Emory team's study will take time. But it's a race against the clock for cases like Mo. Can we remove cataracts in time to prevent their lives from collapsing?

“There is indeed a small window of opportunity in helping these people,” says Mattia. “Once this window is closed, the eye may not be salvaged anymore.”

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Mo says he often thinks about taking his own life. We sit in a dusty, vacant classroom after school one day and talk about this.

Mo had wanted to become a lawyer—mostly because his auntie says he should, since he talks too much. But he had loved school. Each morning, he washes himself by the slum spigot and dresses in his uniform, which he keeps carefully on a hanger to avoid his least-favorite chore, ironing. If his auntie has some money, she gives it to him for rice at lunchtime. He looks forward to seeing Mr. Kamara, his math teacher, who teaches the class fun English phrases and tells goofy stories about birds landing on children's heads before exams for good luck.

When his vision began to decay, school became torturous. Mo started bickering with peers who noticed him falling farther and farther behind. The brawls have escalated, letting up only when his auntie threatens to beat him. His classmates tell him the rumors their parents have heard: that all Ebola survivors go crazy in time. Mo worries that he can already feel the craze coming on. He can't sleep. He can't focus.

“There is a lot of suffering in the provinces,” he utters, suddenly in English, ensuring the translation is clear. “A lot of suffering.” Then he sits quietly, his head resting on a desk, waiting.

