Films

Neglected people and a neglected disease

In the Andean highlands of Peru, a diminutive old lady sits by the roadside. Now and again she sells herbs to passers-by. She wears a trimmed hat and wraps a rug around her shoulders. But it is her nose that draws attention. The leishmania parasite has flattened it and pushed it into her face—the Peruvians call it “the mark of the jungle”. In her previous village, her neighbours gave her a hard time: “they found me revolting” she says, “they treated me terribly: they laughed at me, made jokes about me, and insulted me. My feelings were hurt”. She thought about drowning herself.

Over in southern Nepal, a man works at picking corn. His spleen is swollen, and his skin is beginning to darken—kala-azar means “black fever” in Hindi—but the crop must be gathered before the monsoon hits. Illness is an expensive enough business without forgoing the harvest.

In Ethiopia’s Amhara region, a faith-healer clad in a lively green shawl admits that illness tends not to respond to his ministrations—his bailiwick is more the evil-eye or demonic possession. Still, many villagers continue to visit faith healers; health centres are few and far between, and it is tiring to carry family members on one’s back or a makeshift stretcher, particularly in a country where, among health issues, malnutrition is surpassed only by infectious disease. Therapies—his bailiwick is more the evil-eye or demonic possession. Still, many villagers continue to visit faith healers; health centres are few and far between, and it is tiring to carry family members on one’s back or a makeshift stretcher, particularly in a country where, among health issues, malnutrition is surpassed only by infectious disease. Therapies—his bailiwick is more the evil-eye or demonic possession. Still, many villagers continue to visit faith healers; health centres are few and far between, and it is tiring to carry family members on one’s back or a makeshift stretcher, particularly in a country where, among health issues, malnutrition is surpassed only by infectious disease. In the Andean highlands of Peru, a diminutive old lady sits by the roadside. Now and again she sells herbs to passers-by. She wears a trimmed hat and wraps a rug around her shoulders. But it is her nose that draws attention. The leishmania parasite has flattened it and pushed it into her face—the Peruvians call it “the mark of the jungle”. In her previous village, her neighbours gave her a hard time: “they found me revolting” she says, “they treated me terribly: they laughed at me, made jokes about me, and insulted me. My feelings were hurt”. She thought about drowning herself.

In Ethiopia’s Amhara region, a faith-healer clad in a lively green shawl admits that illness tends not to respond to his ministrations—his bailiwick is more the evil-eye or demonic possession. Still, many villagers continue to visit faith healers; health centres are few and far between, and it is tiring to carry family members on one’s back or a makeshift stretcher, particularly in a country where, among health issues, malnutrition is surpassed only by infectious disease. The scenes are taken from a triad of WHO-produced documentaries on leishmaniasis, available to watch online. Needless to say, the underpinning theme is poverty. Mucocutaneous Leishmaniasis: The Mark of the Jungle largely explores the issue of stigma. Towards the end of the film, we meet Venancio. The father of eight apologetically consults a doctor in Peru’s Cuzco Province. His nose has been badly damaged by leishmaniasis, but he felt unable to attend the clinic sooner because he had to work.

Another participant tearfully recalls how he was ostracised from his community when he became disfigured; doubtless, Venancio encounters the same kind of prejudice. Jorge Alvar (WHO, Geneva, Switzerland)—under whose auspices these documentaries were produced—has pointed out that, across the world, “there are no national policies for reducing leishmaniasis stigma”.

In The Mark of the Jungle and Inside Poverty (which centres on Ethiopia) we learn of traditional methods used to fight the disease. A Peruvian healer recommends forsaking fish with teeth. “People are afraid of the leishmaniasis drugs” he says, “because they hurt the liver”. Sores are often burned or doused with battery acid. In Nepal—the focus of Rajiv’s Journey—the narrator notes that “the last-stop [for patients with kala-azar] are pharmacies and private clinics”. If untreated, kala-azar is fatal. “Kala-azar finished with all my sons” mourns a bearded villager in Inside Poverty, “kala-azar finished with all of us”.

Of the three featured countries, perhaps Nepal faces the most complicated problems. Leishmaniasis everywhere affects the most disadvantaged, but Nepal’s situation is exacerbated by the legacy of the caste system—people don’t often consider female dalits (untouchables) worth taking for medical treatment. Meanwhile, the porous border with India sees a flow of prostitutes back and forth from Nepal. The area is marked by destitution, infectious disease, and drug dependency. One individual—a drug addict and alcoholic—is positive for HIV, hepatitis B, and kala-azar.

All of which brings us back to poverty—cause and consequence of leishmaniasis. It is poverty that drives Peruvians into the jungle to cut lumber or pan for gold. It is poverty that forces Ethiopian villagers to gather sandfly infested cow dung to use as fuel. Poverty means that Nepalese families sleep in the open; and that people in all three countries delay or forgo treatment while they continue to earn for their families. The family in Rajiv’s Journey has a daughter stricken with kala-azar. The narrator estimates it will take 10 years to satisfy the debt incurred by her illness and treatment.

The documentaries—none of which last longer than an hour—neatly explore some of the issues surrounding visceral leishmaniasis in Africa and the Indian subcontinent, and cutaneous leishmaniasis in South America. At places, a firmer hand in the editing suite would have been beneficial, but for the most part these are lucid and well-organised films. Taken as a whole, they serve as a sombre reminder of the knotty intractability of some of the problems faced by those who work in fighting neglected diseases.

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Erratum


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