



The Legacy of Leprosy

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Abstract

As scientists we look for intellectual advancement through every encounter, yearn for new knowledge, and search for ways to further our learning. We are programmed by our nurturing to identify, analyse, and solve. Humans with blinders, we are obtuse in our ignorance; however, our nature, if we allow it, will find emotional growth - some encounters will compel us to introspect, so the learning becomes about ourselves, even as we may struggle to align our (unrealistic and idealistic) views with the (subjectively bleak) reality.

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For most of us, leprosy is a disease of a by-gone age, like small pox or the plague. You can go your entire life without meeting someone afflicted, and may never even have to imagine that the condition exists - out of sight, out of mind, after all. But the truth of the matter is, the ailment is still a reality for some of us. More than 200,000 new cases are diagnosed every year,[1] with the burden heavily skewed toward the developing world. India shoulders the majority of the burden, with 75% of all cases being confined to the subcontinent. Despite the significant numbers, the

disease remains misunderstood, shrouded in misinformation and misconception.

The social stigma associated with leprosy and the embarrassment the patients feel because of disfigurement cause them to ghost-away from conventional society. It wasn't until I was in my first year of medical school that I visited one such "colony" that my hospital worked with. An ardent champion of secular non-conformism, I hadn't ever imagined that such a segregative and isolated society would have a place in the modern world, which I, then a struggling optimist,

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would paint as integrative - celebrating the myriad of peculiarities and differences. What I had failed to comprehend was that the colonies existed because the inhabitants desired it – this was no society of the shunned.

The very existence of a separatist state was in contempt of my then youthful, one-dimensional thought process, for this was a rebellion against the republic - it was not an expression of non-confrontational, unconscientious non-conformism. Ultimately, surrendering to an onslaught of mixed emotions, I had to admit to myself that the colony was self-sufficient, self-reliant and self-aware. I eventually gave in to its absurdism and came to respect its improbable existence as (my) nature and nurture collided.

The inhabitants cared for the other members of their community - out of autonomy and volition and not out of obligation - and the peace that their sequestered existence gave them outweighed any desire to reconnect with the material world. I found that concept hard to grasp at first, but the meaning of it has become more lucid with time.

This is an account of an interaction I had during my early medical school rotations with a gutsy woman who had leprosy. It is often hard to recall the events of the same or the previous day - but effortless to reminisce about an incident in the past - especially if it has had an intellectual or emotional endowment.

One summer morning, about a decade before I met her, Mary, a fifty-eight-year-old multitasking agricultural labourer from South India, woke up with a small swelling on her right arm. She had just finished a course of treatment for a nasal block that had cost her a small fortune, so this new incongruity baffled her. She decided to ignore it at first, but shortly thereafter she developed multiple ulcers

all over her body – they would begin as crops of vesicles that would go on to rupture, heal, and then fissure again.

For two years she tried native medicines and alternative treatments, and offered prayers to every god she could name, but all to no avail. Then began her expeditions to every hospital and clinic in the region, but, in her own words, not even the injections helped. Soon, she began to develop ulcers on her hands and feet, was unable to do manual labour, and after pilgrimages from one health centre to another, in June of 2011, she was diagnosed with Hansen's Disease.

“I had seen the disease on TV, but I never thought I would contract it.” The disease came as a surprise to Mary as she could recall no contact from whom she could have acquired it. A daily wage labourer, she earned Rs. 100 a day doing any work she could find, including carpentry and construction. Her husband, aged about 85 years, used to earn a meagre sum of Rs. 900 per month in his heyday, but that was decades in the past. The couple had no children of their own but had raised the four children of Mary's late sister.

Mary's illness was a heavy burden and she had to mortgage her land. With pride she recalled that despite the sores, blisters, and open wounds that swathed her body, she worked tirelessly. She wasn't the kind who gave up when times got tough, and besides, she had a family to feed, she would remind herself.

Though “slightly” diabetic, she had never been seriously ill before. Prior to her infirmity, the matriarch had a commanding presence. “Even the men were intimidated by me, and I would order them around,” she beamed, swatting gender-roles into the shadows with a regal disposition more natural to the privileged. Today, thin and weak, she

is the ghost of the woman she once was, but despite her aches and pains, she sat up to speak with me, as though she had something to prove to herself.

“I don’t understand the disease - after all, I don’t have an education”. There was a look of longing in her eyes as the words left her mouth, and she glanced away, the creases on her forehead flattening as she imagined a life that could have been, or perhaps that was what I wanted to believe. “No one in my village knows what I am suffering from...they say I was bitten (by something).”

The infection has affected the ulnar nerve in her right arm and has resulted in the clawing of her fingers. Her forehead is riddled with sores and oozing pustules. Crusted lesions cover her cheeks, neck, upper back, abdomen, arms and thighs. “I cannot even comb my hair.” Her feet are cracked and dry, like a lakebed in a drought. Her muscles ache and she suffers from recurrent fevers. The secondary infections have not been kind. Her skin itches terribly - “It feels like there are insects crawling beneath my skin,” she sighs.

“I thought I disliked hospitals, but there is something comforting about them, too. The care with which the doctors and nurses have looked after me has amazed me. I expected a very mechanical practice, but there is compassion and kindness here...that is rare.” I wondered if that was true, disillusioned as I was by the general public’s view of the profession that I so passionately pursued. In the end, I allowed myself to accept the small victory – the medical fraternity had a new champion and friend.

Mary has responded well to her treatment, and her doctors are buoyant since she has a good prognosis. She is strong-willed and is confident and determined to get healthy again. “I will take my medicine for however long it is needed. I have special scrub baths every day, and eat bananas and drink coconut water to help build my immunity. I’m not afraid, I know my doctors will look after me.”

Ethical Considerations:

Mary’s permission to pen her story was obtained in writing from her. She insisted that I use her real name.

Reference

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1. World Health Organization. Leprosy elimination: Epidemiology [Internet]. 2015 [cited 2019 Mar 14]. Available from: <https://www.who.int/lep/epidemiology/en/>
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